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ABSTRACT

This practicum report addresses the educational needs of students with the visual disability of ocular or oculocutaneous albinism. Two booklets were developed, published, and distributed--one for regular education teachers of children with albinism and one specifically about the very young child with albinism. The booklets discuss the special needs of these children and interventions and devices available to assist them. Evaluation of the booklet for teachers by 20 educators of the visually impaired was highly positive, as was evaluation of the preschool booklet by 5 preschool day care teachers. A survey completed by 107 parents also supported the validity and usefulness of the teacher booklet. Additionally, an international survey which received 41 responses indicated a need for the type of information presented in the booklets in other countries. Appendices include the checklists used for both educator and non-educator groups, a copy of each booklet, and various letters distributed during the course of the practicum. (Contains approximately 240 references.) (DB)

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Albinism: Improving Teacher and Caregiver Strategies for Meeting the Special Needs of Children with the Visual Disability of Ocular Albinism or Oculocutaneous Albinism (Birth to Age 14)

by

Julia Robertson Ashley

Custer 41

A Practicum II Report Presented to the
Ed.D. Program in Early & Middle Childhood
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Education

NOVA UNIVERSITY

1992

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PRACTICUM APPROVAL SHEET

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Approved:

December 17, 1992
Date of Final Approval of Report

Mary Ellen Sapp
Mary Ellen Sapp, Ph.D., Adviser

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I would like to thank Mr. Lee C. Rawl, principal of Honea Path Elementary School, who has been supportive of this work. Special thanks go to my husband Allen and to my daughter Mary Lin, who have given me first-hand experience with the dynamics of visual disability upon the family.

Finally, I would like to express my appreciation to Dr. Polly Peterson and to Dr. Mary Ellen Sapp, my advisers for the Practicum II project. Their assistance and suggestions have been invaluable in guiding me through this work.

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ABSTRACT

Albinism: Improving Teacher and Caregiver Strategies for Meeting the Special Needs of Children with the Visual Disability of Ocular Albinism or Oculocutaneous Albinism (Birth to Age 14). Ashley, Julia R., 1992: Practicum Report, Nova University, Ed.D. Program in Early and Middle Childhood Education.

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This practicum was designed to address the lack of information for teachers in the educational needs of students with the visual disability of ocular or oculocutaneous albinism. The writer's goals were to determine educational strategies appropriate for children with albinism and to develop a method of disseminating this information to an international community. Participants were from the United States, Canada, Europe, and other countries.

The writer developed a booklet for teachers which was published and distributed through four national and international organizations. The writer assessed the participation of a sample of participants at the end of the implementation period. Communication with participants was maintained by telephone, U. S. mail, and personal contact.

Parents and teachers reported an increase in understanding of educational needs of children with albinism. International contacts indicated that the information would be useful and appropriate for non-American educators.

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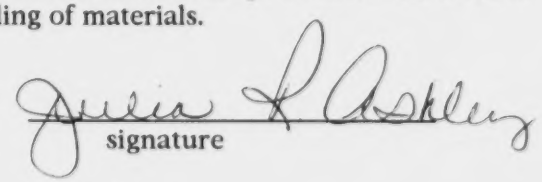
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CHAPTER I

INTRODUCTION

Description of the Setting

The setting for the practicum was an elementary school located in a rural community serving students with the visual disability of albinism. The school has kindergartens (4 and 5 year old), Grades 1-4, two resource rooms for students with learning disabilities, and a self-contained special education class. The school is located in the sixth largest county in the state, which encompasses 749 square miles and has a population of 149,340, according to the 1990 census information.

The population of the area served by the school district is 20,000. The average daily enrollment of the school district is 3,500 with an average daily attendance of 96.3%. Percentage of enrollment classified as nonwhite is 20%, and records indicate 22% of the pupils in the district who are eligible for free or reduced lunch. Percentage of graduates entering college or post-secondary technical institutions is 38%; only 4% of the district students drop out between Grades 9-12 Twenty percent of the students in the district are identified as gifted, the second highest number in the state (district records). The district is served by a professional staff with a student-teacher ratio of 20 : 1. Forty-eight percent of the district employees have master's degrees; 14% of the professional staff have sixth-year certificates or doctoral degrees. The average number of years of

experience of teaching staff is 12 years with a district-wide teacher turnover rate of 6%, the sixth lowest in the state. Eighteen percent of the district teaching staff is male.

The school district is governed by a Board of Trustees consisting of seven members elected by the people. A superintendent appointed by the Board is employed to serve as the chief administrator of the school district which operates seven schools for 3517 students in grades K-12, and employs a professional staff of 250 and a service staff of 100. A Career Educational Center is operated jointly with a neighboring district for high school students following a technical preparatory curriculum. All schools are accredited by the state Department of Education and the Southern Association of Colleges and Schools which requires the schools to meet minimum quantitative standards and qualitative standards for class size, personnel, school facilities, libraries, instructional materials, and curriculum. The district philosophy states:

> We believe that education is a means by which an individual can participate in experiences that foster the growth and development of the total personality and is the means through which society can promote and develop democracy as a way of life. We believe that our schools should provide the best possible conditions for enhancing social, emotional, physical, spiritual, and intellectual development so that the individual will accept his role and responsibilities in a free society. We believe that all activities of the schools should contribute to the development of each individual so that he may acquire not only knowledge and skills but also wholesome attitudes

toward life, good qualities of citizenship, desirable character traits, and achieve self-fulfillment (district records).

Financial information concerning the district reflects a district with somewhat limited financial resources. The assessed valuation of the district is $31 million. Twenty-eight percent of the revenue for operating funds is obtained from local sources. Revenue for operating funds received from state sources is 67%, with an additional 5% of the revenue received from federal sources. The tax levy in mills for current operations is 77 mills; the tax levy in mills for debt service is 17 mills. The local tax effort ranks 53rd out of 91 school districts in the state.

The school in which the practicum took place is located in a town with a population of 7,346. According to information obtained from the 1990 census of the county, median household income is $23,354. Racial background of the residents of the county is as follows: 82.6% white, 16.6% black, .1% Indian, .1% Hispanic, .2% Asian, and .4% other. A total of 26.89% of the total population is of school age (ages birth through 17 years). Educational background of the area presents a population in which 52.7% have less than a high school education. Only 10.1% of the population are college graduates, but an additional 11.8% have between one and three years of college or technical training.

The Writer's Role and Responsibilities

The writer served as a teacher in the elementary school as well as an independent consultant for the visually handicapped children in the region and is the only teacher certified in education of students with visual disabilities at the time of the practicum in the large rural county comprised of five school districts. The writer is the itinerant and consultant teacher of students with visual disabilities for the district.

Additional responsibilities of the writer were as a member of a state-wide parent support group for family members of children with visual disabilities and as the legislative liaison for the state chapter, as well as being a member & state contact person for the national organization serving individuals with albinism, and a member of the affiliated international organization.

The writer's qualifications are a B. A. in liberal arts, M.A.T. in library science, Ed.S. certification in information science, plus advanced graduate work in education of the visually impaired and computer technology. She holds teacher certifications in library science, special education (visual disabilities), English, social studies, and elementary education. The writer, who has 19 years experience in education at the elementary school, middle school, and high school levels, was named Outstanding Student of the Year in 1991 by the Council for Exceptional Children, Division for the Visually Handicapped. She is a member of the State Department of Education's Excellence in Education committee and serves on the Special Education subcommittee. She was the recipient of the first scholarship ever given to prospective teachers of the visually handicapped by the National Association for Parents of the Visually Impaired (1990) and was the first recipient of the Council for Exceptional Children, Division for the Visually Handicapped (DVH)'s Outstanding Student of the Year award (1991). She has written articles on educational aspects of visual impairment in children and on adaptive computer technology for parents of children with visual disabilities and has had an article about educational needs of children with albinism accepted for publication by RE:VIEW, a professional journal for educators of the visually handicapped.

For the past four years, the writer has been employed as a teacher at the elementary school which is serving as the work setting for this practicum and has done private consultation work with families of children with visual disabilities

throughout the state. She has presented workshop programs on visual impairments and on albinism to parent and teacher groups.

CHAPTER II

STUDY OF THE PROBLEM

Description of the Problem

The problem addressed by this practicum was that teachers of students with albinism were having difficulty meeting the educational needs of their students. Teachers of students with albinism throughout the writer's state were facing the dilemma in addressing the educational needs of their students due to the unusual characteristics associated with this condition and the extreme rarity of the occurrence. There is little information in professional literature which addresses the needs of children with albinism.

Documentation of the Problem

In a 1991 telephone survey of 10 parents of children with the visual disability of albinism, nine parents in eight states of the United States and one Canadian province, and one parent from Great Britain related that they believed their child's teacher had difficulties in meeting the educational needs of their children.

Six of the 10 parents interviewed reported being given misinformation by medical doctors concerning the educational prognoses of their child, such as having been told by pediatric opthalmologists that their child would be unable to

attend regular school, would "never be able to read" (personal conversation, Allen Ashley, November 28, 1991), and would be functionally blind. The parents all agreed on a need for help in assisting their children in the area of education. In a telephone survey of six teachers of the visually handicapped who were from a four-state area, the writer was told by all six teachers that only minimal discussion had been given to the condition of albinism during the professional preparation of the teachers. These six teachers had received their preparation at different universities throughout the United States.

Only four articles on the topic of albinism were found during manual and computer searches of the ERIC database and other education databases for the time period 1926-1990. Albinism is a term found in the ERIC database.

In a review of two standard textbooks in foundations of education for the visually handicapped used to instruct prospective teachers of the visually handicapped, there was only a minimal amount of information given about the condition of albinism in each of the books. These books are standards used around the United States, and may help explain why American teachers have such limited knowledge of this condition. Not all university preparation programs in visual disability offer a separate course in the anatomy/ physiology/ pathology of the eye which would give more detail about individual etiologies (Head & Bishop, 1992); most states require a course in educational procedures for certification in education of the visually disabled, but not all require an anatomy course.

In a 1991 telephone discussion with the president of the National Organization for Albinism & Hypopigmentation, Janice Knuth stated that teachers from states across America and from Canadian provinces have contacted the organization to learn of educational strategies which could help their students. She also stated that a major concern of parents of children with this condition is

the lack of information available to their children's teachers. In a telephone conversation in 1991 with Mrs. Eileen Hudson, president of National Association for Parents of the Visually Impaired (NAPVI), she related that there was a need for information about this condition which could aid teachers in better meeting the needs of their students with albinism. Correspondence with Mr. James Wiseman of Scotland, the corresponding secretary for the Albino Fellowship, indicated that information for teachers was needed in Europe and other countries, as well.

Causative Analysis

The children who have this condition represent such a very small portion (4%) of a low incidence population (.07%) that it is difficult for most educators to evaluate enough children to assess techniques which will be helpful to these children. Research with many different etiologies has been limited because of the difficulty in obtaining representative samples (Adrian, Miller, & De L'Aune, 1982). According to Kinnear, Jay, & Witkop (1985), the prevalence for oculocutaneous albinism is 1:39,000 in United States Caucasians and 1:28,000 U. S. blacks. The condition of ocular albinism is even more rare, occurring with a prevalence rate of 1:50,000 (Kinnear et al., 1985).

There is a small population involved with this condition and few individuals located in any one geographic area, so there is a paucity of research available on educational aspects of albinism.

Children with albinism seem to function moderately well in school settings, so teachers often may not realize that the child is having difficulty. Of the population of children with albinism, 86% of these children are legally blind (Haefemeyer, 1988).

Briefly stated, the problem was that teachers of children with albinism had

difficulty in addressing the educational needs of their students, and parents were unable to provide the professional support to assist these educators.

Relationship of the Problem to the Literature

Albinism is any congenital hypopigmentation (lack of pigmentation), which can occur in plants, animals, and humans. In the human being, it affects the eye in the form of reduced visual acuity and nystagmus, and causes moderate to severe visual impairment. References to albinism have been recorded throughout history, the earliest citation raising speculation that Noah of Biblical fame had albinism. Descriptions of persons with albinism have been found in the writing of Pliny and Ptolemy (Courtney, 1966). An hereditary condition (Noah's parents Lamech and Betenos were either brother and sister, or first cousins, depending on the translation of a badly preserved scroll from the Dead Sea caves) (Sorsby, 1958), albinism does not occur solely from intermarriage. An individual may be a carrier without being aware of the condition.

Descriptions found in past research involving individuals with albinism have at times failed to meet modern ethical standards for description of subjects. Beckham (1946), in a study of albinism in black children in Chicago, IL, described family members of the children as "shiftless and inept" (p. 202), "a ne'er do well" (p. 211), a "neurotic" (p. 211), and that albinism was "a sport in nature" (p. 207). There has been a scarcity of literature related to the educational needs of children with albinism. A wide variety of literature from the medical field has examined the physical abilities of individuals with albinism (see Appendix A), yet even the medical community exhibits differing views of the condition. Medical experts deal primarily with the needs which can be met with optical treatments. These treatments range from spectacles and contact lenses to state of the art electronic enhancements.

There is not uniform agreement in the medical field concerning the most appropriate optical treatment for children with this condition. There are certain doctors who favor bifocal spectacles, low vision devices, contact lenses, or no optical treatment at all. It is hardly surprising that teachers have not received educational support when the medical field is unable to decide about the most appropriate visual aids. Fonda, Thomas, and Gore (1971) noted that the types of albinism accounted for approximately five percent of ocular defects causing legal blindness. They advocated that use of strong reading additions such as bifocal spectacle lenses were more appropriate for children with albinism than were low vision devices. Their study found that persons with albinism rarely had binocular vision, and usually used one eye for reading. They noted that many "highly trained and educated albinos are able to find professional employment and to perform duties one usually associates with a need for normal vision" (p. 35), attributing this to the ability to read printed material in standard size print and to perform near vision tasks well. The study noted that Braille is not appropriate as a reading medium for persons with albinism and questioned the need for large print as a reading medium. Wharton and Haefemeyer (1988) noted that large print is useful with students with albinism, in contrast to the study by Fonda et al. (1971). It may be noted that more modern low vision devices could have been developed during the period, advanced technologies for producing materials in large print with less blur and distortion, and other factors could have influenced the change. There has been no change in the view of Braille as an inappropriate mode of reading and writing for children with albinism (Wharton, S., Dempsey, N., & Ashley, J., 1992). The number of individuals able to be assisted with new innovations in optical and nonoptical aids is growing rapidly (Grieg, West, & , Overbury, 1986). Children with visual disabilities need to be provided with the aids and skills which will assist them to utilize their vision to the best of their

abilities (Lubke & Corn, 1983). Children with albinism have acuities ranging from 20/80 to 20/800, and often have visual acuities fluctuate from day to day among individual children (Dempsey, 1991).

Doctors may have difficulty in identifying the condition of albinism in newborn or very young infants because symptoms such as nystagmus may not have developed yet and skin tone may seem no different from that of other babies (Tylor, 1987). None of the states in the U.S.A. require the testing of vision under school age (Gardner, Morse, Tulloch, & Trief, 1986). A report by Baird and Hemming (1982) indicates that during neonatal vision screening, such visual responses as a lack of sustained fixation might be an indicator of nystagmus, one of the primary ocular characteristics found in albinic individuals. This might be a significant indicator of a serious visual impairment. According to a study by Wilson, Mets, Nagy, and Kressel (1988), it was found that the albinic retina is very similar to that of the normal human infant retina, which also exhibits low acuity. Researchers cited in the study noted that infant retinas lack a foveal pit and that cone density is far less than adult densities. These are similar to the retina of adults with albinism. Acuities of all infants are below that of adult levels; according to Corn (1983), children do not normally attain visual acuity of 20/30 until approximately kindergarten age.

Early diagnosis of albinism is important because European specialists believe that the visual impairment may be reduced if treated in infancy (Harris & Heyman, 1973; O'Donnell & Livingston, 1991). It has been suggested by various eye specialists in Europe that proper vision care of persons with albinism is especially important during the first four months of life, but this is not accepted by most vision specialists in the United States. Treatment with either pinhole contact lenses or pinhole spectacles eliminate or minimize the ocular characteristics normally associated with albinism (Harris & Heyman, 1973;

O'Donnell & Livingston, 1991). After the age of four months, however, this reduction is not possible.

Persons with albinism generally have high refractive errors and large amounts of astigmatism (Abadi & Pascal, 1989), so optical correction is needed where possible. Spectacle lenses and contact lenses both can be used with some individuals, depending upon the patient's preference. Most persons surveyed preferred glasses to contacts (Abadi & Pascal, 1989). One reason given involved the discomfort of the movement of the eye due to nystagmus. The constant ocular movement of nystagmus, found in all individuals with albinism, can be uncomfortable or even painful.

Dr. Marvin Efron, a low vision specialist and instructor at the University of South Carolina, noted that low vision devices are of tremendous help to persons with albinism. He stated that with the advances in low vision technology in the past fifteen years, children with albinism have a visual impairment which can be dealt with effectively in educational settings (Efron, 1990). William Shalinsky, an adult professional with low vision, believes that "a piecemeal approach to low vision services is a disservice to low vision consumers" (p. 355) and that services should be provided in a multidisciplinary and coordinated fashion (Shalinsky, 1983). Low vision devices or aids can be used for near or distance vision activities.

Vander Kolk and Bright (1983) found that the general public held many misconceptions about persons with albinism. Some members of the public have considered individuals with albinism to be "freaks" (Vanker Kolk & Bright, 1983) and ridiculed them. One misconception is that albinism is a disease, rather than a medical condition. A disease is an illness; a condition is not germ-related or a sickness. The condition of albinism is life-long, in contrast to a disease which can be cured or treated. The study by Vander Kolk and Bright (1983) found that

there was a "common lack of information" (p. 49) among the general public concerning albinism. "Albinic individuals surveyed and interviewed reported life-long experiences with an insensitive and unaccepting public" (p. 50). It was found that mental and emotional stresses are no more widespread in the population of persons with albinism that in the general public. Wells (1978) describes a person with albinism as "suffering from a disabling disease because in addition to other defects, he is sure to have impaired vision which is greatly handicapped by nystagmus" (p. 3). This is considered by most modern experts to be an example of misinformation. Albinism is a medical condition, but it is not a disease (Vander Kolk & Bright, 1983). The condition lasts from birth until death and cannot be cured nor treated medically in order to improve the albinism. Optical treatments can improve the clarity of vision, but nothing in medical science at this point in time can be done to correct the lack of a fovea in the retina or to change the routing of the optic nerves through the brain. An illness can respond to medical treatment; a condition cannot.

Psychosocial aspects of albinism have a profound impact upon individuals with this condition. Children with albinism often experience episodes of name calling and derogatory remarks due to their condition and encounter difficulties and harassment due to their condition (Knuth, 1992; Vanker Kolk & Bright, 1983). Waugh (1988) reported that 88% of adults with albinism surveyed reported having experienced discrimination in elementary through high school.

Low vision is defined as "insufficient vision to be able to do a desired task" (Evers, 1982, p. 22). Children with albinism have a severe visual disability, but are able to use their vision for functional purposes, as opposed to children who are functionally blind. The child's first teachers will be his or her parents, and their reaction to the disability can have far reaching effects. According to Akeson, (1990), a child's visual disability has a lifelong influence on the family. The

family is vitally important for early intervention, without which the child may become developmentally delayed in social and emotional areas (Barraga, 1983; Wolery, 1991). The intervention should be introduced as early as possible in order for the child to develop skills on a level equivalent to their fully sighted classmates (Guralnick, 1991; O'Donnell & Livingston, 1991; Olson, 1981). These delays can be avoided or reduced by early sensory stimulation (Warren, 1984).

Early intervention is becoming more widespread, and as of 1990, over 600,000 children with disabilities of varying types were being served in early intervention programs (Hebbeler, Smith, & Black, 1991). The goal of the early interventionist is to delineate an individualized program which will identify the areas in development which are delayed, and to devise the methods to enhance the areas of development (Dimidjian, 1989). Administrators as well as teachers recognize the value of early intervention programs, with a survey of district superintendents indicating that 100% of the heads of school districts believed that early childhood special education programs were beneficial (Gallaher, Maddox, & Espinosa, 1984). Early intervention services are family centered (Bailey, Palsha, & Simeonsson, 1991; Dunst, Johanson, Trivette, & Hamby, 1991), being primarily based in the home during the infancy and toddler years.

As the child enters the school years, additional pressures impact upon parents. Some parents, according to a study by McDonnell (1987), have concerns that their child would be isolated from regular classroom peers and not have a successful social adaptation or that their child might possibly lose other support services when integrated into a regular classroom. Other parents have concerns that use of low vision devices can be considered as stigmatizing rather than something which encourages independence (Gardner & Corn, 1990). Aids such as telescopic spectacles, which permit the individual to view distant objects, have been disliked by many low vision students because they consider them

unattractive, and they don't want to appear different from other children (Overbury, Greig, & West, 1982).

Emotional stresses during the school years can be compounded by albinism. Fifty percent of albinic adults noted that they had felt confused feelings during their high school career (Waugh, 1988). Reactions of strangers has an effect on the child's self-esteem. According to Tylor (1987), in discussions with persons with albinism, "all felt that albinism had made others wary of them to a greater or lesser extent at various times in their lives" (p. 22). Often, adults with albinism are not informed of the aspects of their condition. Waugh (1988) found in a study of adults with albinism that 78% had never had albinism explained to them in a clearly understood fashion, and that 63% had been given no explanations whatsoever.

Terminology used to describe children with albinism has had negative or derogatory connotations. Haefemeyer (1991) cites the term "albino" as having been used in a hurtful manner and that the term stresses the condition rather than the child. Misinformation or lack of information about the condition of albinism can cause stress on families of these children (Tylor, 1987; Vander Kolk & Bright, 1983). Non-Caucasian parents of children with albinism have often had to deal with suspicions of adultery with a person of another race or other mistaken impressions by uninformed members of the public (Vander Kolk & Bright, 1983). Parents have reported being given incorrect information by doctors (Ashley & Cates, in press).

The decision as to the most appropriate educational placement for the student with albinism must be decided after an assessment and evaluation of the student (Fewell, 1991; Silberman, 1981; Swallow, 1981). Most children who are low vision attend a regular school in their home area with support from a specialist teacher and other consultants (Burd & Bender, 1986; Goldie,

Gormezano, & Raznik, 1986). Special services of a teacher of the visually handicapped may be provided via an itinerant teacher, resource room, or special class (Silberman, 1981).

An appropriate placement is necessary to ensure the least restricted environment for the child's abilities. Use of a special resource room program to help students fit into the school program can be considered to have "disjointed incrementalism" (Stainback, 1985, p. 147). Stainback defines this as "discontinuities or interruptions that occur in a student's educational program, when he or she has to travel to and from 'regular' and 'special' programs" (p. 147). Appropriate educational decisions can be made only after direct observation in the classroom environment and in the home (Bradley-Johnson, 1986).

According to studies by Corn and Bishop (1984) and Hill, Guth, and Hill (1985), legally blind or low vision adolescents did not perform as well as totally blind students in certain areas of knowledge. They cited a possible cause for this problem as the difficulty encountered by low vision students in noting important details in their environment; with totally blind children, these children receive special instructions to help compensate for this loss (Corn & Bishop, 1984). Children with albinism and other low vision conditions are apt to be overlooked due to the need to instruct children with more serious visual conditions. According to a study by Jan, Freeman, and Scott (1987), the majority of services provided by schools are for those children who have little or no functional vision even though these children represent less than one-quarter of the children eligible for services for the visually handicapped. The children in the low vision population will represent an even greater proportion of the population of visually handicapped in the future (Daugherty & Moran, 1982). The low vision population constitutes approximately 80% to 90% of the population of visually

handicapped (Corn & Coatney, 1984).

Due to the dramatic physical appearance of some types of albinism, many members of the general public do not realize that albinic individuals also have a severe visual impairment. Waugh (1988) found that only 38% of adults with albinism believed that the general public understood that they had visual limitations. Waugh notes that this indicates the extent to which persons with albinism can cope with their disability and conceal visual difficulties from others.

Vocational opportunities of students with albinism may be limited due to their condition. The unemployment rate of individuals with visual impairments is significantly higher than those with normal vision. According to a study by Wolffe, Roessler, and Schriner (1992), unemployment in the general population was approximately 8%, as opposed to approximately 20% in the population of the visually impaired. Adults with albinism report that their greatest limitation caused by the condition is the inability to drive an automobile (Waugh, 1988). Corn and Bishop (1984) reported that unless low vision students are instructed in methods to maximize their visual abilities, the student will lose the potential for learning skills necessary in daily life.

Use of low vision devices can improve low vision individuals to increase their visual functioning dramatically, yet according to Burns (1972), a population as low as ten percent of these students receive direct instruction in utilization of low vision devices.

A study from a child development center in Scotland reported that children with albinism had higher than average intelligence, but that their verbal IQ scores were often higher than their performance IQs (Haefemeyer, 1988). This type of discrepancy was not found in children with other etilogies of visual disabilities. The WISC-R (Wechsler Intelligence Scales for Children-Revised) was used to evaluate the children. The WISC-R is a standardized test of general

intelligence, with norms for American children aged six to 16 years (Gutterman, Ward, & Genshaft, 1985). The test did require the use of visual scanning and fine visual discrimination, which caused difficulties for the visually impaired children (Haefemeyer, 1988). Haefemeyer (1988) reported that researchers conducting the study postulated that the children with albinism "are uniquely handicapped in their performance abilities relative to their verbal skills by virtue of their albinism, and that their anomalous visual pathways and visual association areas may form the basis for this discrepancy" (p. 2). Haefemeyer (1988) explains that the misrouting of nerves through the brain from the eyes seems to cause difficulties with performance IQ of children with albinism. Haefemeyer, a medical doctor, notes that parents of American children with albinism have reported to him that their children appear to perform extremely well orally but have difficulty when doing the same work on paper.

Identification of children with visual disabilities and giftedness can be difficult (Corn & Scholl, 1990). Tests usually accepted for such programs as the gifted and talented can have barriers for a child who is visually limited. These children must be carefully assessed in order to identify their strengths and provide appropriate services (Corn & Scholl, 1990).

It is very possible that a child with albinism might seem to function extremely well and that there would be doubts that a special educational program would be really necessary for the child. Children with this condition are extremely adept at hiding their disabilities and appearing to function well (Vander Kolk & Bright, 1983). The official position of the Division for the Visually Handicapped of the Council for Exceptional children is that "every infant, child, and youth with a visual handicap is entitled to the services of a teacher of students with visual handicaps, regardless of the severity of the disability or the presence of additional handicapping conditions" (Spungin & Ferrell, 1990, p. 15).

Only by having services provided by a teacher with special educational preparation in the area of visual disabilities will the child with albinism be able to receive the appropriate educational services.

Cameron (1979), an adult with albinism, notes that from early childhood he had been told that he might not be able to do certain things, when in fact the assumption had been made when he was too young to be able to effectively communicate his abilities. He notes that although he is legally blind, his reading activities are not limited to "reading cards of letters stuck on walls" (p. 28). His point is that parents and teachers should allow the child to try to develop his or her school and extra curricular activities without prejudicing the child as to what he can or cannot do. Genesnsky (1978) notes that most individuals who are partially sighted and legally blind will never become functionally blind. Persons with albinism belong to this group.

The condition of albinism presents many difficulties and unique features to the parent and to the educator. These particular features are found in no other ocular condition. The literature reviewed shows a clear correlation between the needs of low vision children and the usefulness of appropriate special educational strategies. The children with albinism have needs which may be partially met by general low vision techniques, but have other specialized needs which must be addressed by etiology. The literature also shows that these needs are not being met at this time by current materials available to parents and teachers.

CHAPTER III

ANTICIPATED OUTCOMES AND EVALUATION INSTRUMENTS

Goals and Expectations

The primary goal of this practicum was to devise strategies which will assist teachers and parents of children with albinism to better serve their educational needs and to make these strategies available in the United States, Canada, United Kingdom, and Europe.

Expected Outcomes

The expected outcomes of the practicum were:

1. Teachers of children with albinism who participated in the practicum would indicate an increase in understanding of the program needs of these students. The outcome was to be assessed by surveying the teachers who had agreed to participate in a follow-up procedure at the end of the eight-month implementation period (see Appendixes B and C), along with a group of preschool teachers who participated in the program in a component added in month 5.

2. Parents who participated in the practicum would indicate an increase in satisfaction with the support materials available for educational needs of children with albinism. The outcome was assessed through use of a checklist

which was completed by parents at the end of the implementation period (see Appendix D).

3. Individuals who have an interest in children with albinism would be surveyed on an international basis to determine the need for assistance in other countries. This was assessed by an evaluation tool sent to the individuals who belong to the Albino Fellowship (see Appendix E).

4. A booklet which detailed the educational needs of children with albinism would be developed and made available to parents and teachers on an international basis (see Appendix F). Acceptance of the booklet by a state, national, or international organization was considered achievement of this outcome.

Measurement of Outcomes

A log was kept of parent and teacher interviews as well as telephone contacts in order to record the progress of the practicum. The implementor of the practicum was the writer.

In consideration of the options for evaluating the achievement of outcomes, the writer planned to include a checklist and self addressed stamped envelope with each booklet disseminated. Parents and teachers would complete the checklists; the number returned would be compared with the number of checklists originally disseminated. Assessment of the checklists, interviews with a sample of parents and teachers, and interviews with the heads of the national and international organization would be used to evaluate the achievement of Outcomes 1-4.

CHAPTER IV

SOLUTION STRATEGY

Discussion and Evaluation of Possible Solutions

The problem to be addressed by this practicum was that teachers of children with albinism had difficulty in addressing the educational needs of their students, and parents were unable to provide the professional support to assist these educators.

Review of the Literature

While visually disabled children are the smallest group among students in special education programs, they have the most unique and differentiated requirements (Akeson, 1990). Diminished visual capacity in a young child poses a unique challenge to parents and teachers because the loss limits access to the information and feedback in the learning process (Zambone, 1989). Early intervention into the child's learning process is necessary to help alleviate the lack of visual learning which comes naturally to sighted children (Hart, 1984; Moore, 1984; Zambone, 1989). According to Smith (1991), "the majority of learning, possibly as great as 80%, occurs through the use of the visual sense" (p. 18). A visual disability can cause difficulties in the child's basic understanding of physical and spacial aspects of the world (Bigelow, 1992). The child with

impaired vision needs intervention with two main focuses: ascertaining that the visual handicap does not hinder the child's development and working to encourage the child to utilize the utmost visual functioning (Zambone, 1989).

Of all of the services and resources available to children with visual disabilities, the most important one is the family (Buzzelli, 1989; Zambone, 1989). According to Griffin (1981), a major problem in the low vision population is the child's lack of opportunity or motivation to actively explore in the environment. O'Donnell & Livingston (1991) have supported the importance of allowing the child to explore his or her world. Parents, as the earliest teachers, must participate in the efforts to encourage the child to explore.

Parental doubts about the success of mainstreaming seem to be inappropriate, according to a study by McDonnell (1987), which revealed that the interviews indicated that the percentage of parents who believed their child was interacting with regular classroom peers and not isolated from the children was 86%. Ninety five percent of the parents in the same study reported their children were participating with full access to extra curricular activities sponsored by the school. Some parents have worried that their child will possibly lose other support services when integrated into a regular classroom. McDonnell (1987) reported that 80% of parents with children in a regular, integrated classroom reported that their children had not lost services such as occupational therapy or physical therapy. According to reports of parents of children in regular classroom settings, the majority of the children had few incidents of mistreatment or rejection from their peers (McDonnell, 1987). Some parents had concerns that use of low vision devices can be considered as stigmatizing rather than something which encourages independence (Gardner & Corn, 1990). Teachers should inform parents as well as the student of the purpose of the aid and help them learn to support their child in the use of the aid.

Children with albinism have visual acuities ranging from 20/80 to 20/800; therefore, the need for the type of reading medium will vary according to the needs of the individual child (Dempsey, 1991). An economic consideration with practical implications for schools is the cost of large print books. Standard size print books are readily available for students with impaired vision. Large print books are not always available, and when they are, the cost can be as much as ten times the cost of the regular book (Gardner & Corn, 1990). The use of low vision devices with regular print material is less expensive in the long run than use of large print, and has the advantage of allowing the student access to regular classroom materials. According to Gardner & Corn (1990), if children are able to use standard sized print, they will be better prepared for future employment where use of standard size print is required. Employment opportunities for students with visual limitations are an area of concern for educators, who must strive to prepare the child to adapt and suceed in the general work force in adult years (Wolffe et al., 1992).

Reading material can be adapted for the student with albinism in larger print or through use of low vision devices. Dempsey (1991) considers contrast to be more important than print size in determining the reading medium. Gardner (1985) also considers contrast to be vitally important in reading materials for low vision children. Low vision devices may assist the student in achieving greater access to the learning environment. These aids can be extremely expensive and the student may need several aids for different purposes. Most costs of low vision devices are borne by the parents of the student. Insurance companies tend to exclude eyeglasses and optical aids from coverage; according to Kirchner (1984), students covered by Medicaid are more likely to have coverage for low vision devices than those students who are insured through private policies.

Terminology may have an effect on the self-esteem of persons with visual

impairments. According to Haefemeyer (1991), language used to describe minorities and persons with disabilities has changed over the past ten years. Currently, the term "handicapped" has tended to be dropped and replaced by "person with a disability" and this change is becoming reflected in persons with albinism. Haefemeyer states that "the word 'albino' has been used in a hurtful way" (1991, p. 16). He advocates the use of the term "person with albinism" rather than "albino" in order to reflect the individual who has a condition instead of emphasizing the condition as determining the individual.

Many children who have albinism have also been found to have above average intelligence. Consideration for special programming is necessary for children who are visually handicapped and also gifted (Corn & Scholl, 1990). A study from a child development center in Scotland reported that children with albinism had higher than average intelligence, but that their verbal IQ scores were often higher than their performance IQs (Haefemeyer, 1988). The WISC-R (Wechsler Intelligence Scales for Children-Revised) was used to evaluate the children. The test did require the use of visual scanning and fine visual discrimination, which caused difficulties for the visually impaired children (Haefemeyer, 1988). Haefemeyer (1988) reported that researchers conducting the study postulated that the children with albinism "are uniquely handicapped in their performance abilities relative to their verbal skills by virtue of their albinism, and that their anomalous visual pathways and visual association areas may form the basis for this discrepancy" (p. 2). Haefemeyer (1988) explains that the misrouting of nerves through the brain from the eyes seems to cause difficulties with performance IQ of children with albinism. Haefemeyer, a medical doctor, notes that parents of American children with albinism have reported to him that their children seem to perform extremely well orally but have difficulty when doing the same work on paper. He believes that this would

be an excellent topic for further research.

Gifted and talented students demonstrate superiority (or potential for superiority) in the following areas: "general intelligence, specific academic aptitude, creative or productive thinking, leadership, the visual or performing arts, or any combination of the above" (Corn & Scholl, 1990, p. 7). The gifted/visually handicapped are defined as those children who are identified as being both gifted and visually handicapped (Corn & Scholl, 1990). "An appropriate education requires the cultivation of the student's special gifts and talents, meeting unique needs as a visually handicapped person, and special consideration of the issues facing those with dual exceptionality, i.e. giftedness and disability" (Corn & Scholl, 1990, p. 7). The children who need services in order to meet the needs of the two exceptionalities require programming which is responsive to their unique needs in four areas: "identification, curricular modifications, trained staff and support service, and psychological needs and counseling" (Corn & Scholl, 1990, p. 7).

Mainstreaming, the integration of handicapped students with their regular classroom peers (Burstein, 1986), has never been a topic without controversy, and this continues to be the case. Most discussions concern the effectiveness of mainstreaming and if it really works (Jenkins, Speltz, & Odom, 1985; Stainback, 1985). The attitude of regular classroom teachers and school administrators has a definite impact on the success or failure of mainstreaming a handicapped child into the regular classroom (McDonnell, 1987). There is general agreement that placement in special education classes does affect a student's self-esteem, either in a negative or positive manner (Battle & Blowers, 1982; Workman, 1986). Short term placement in special educational settings has a tendency to enhance the student's perception of self-worth (Battle & Blowers, 1982); it was determined that students in special education classes had an elevated sense of self esteem and

views of their own abilities. Stainback (1985), endorse having special educators placing more emphasis on working with regular classroom teachers to make modifications in the structure of the regular classroom to accommodate a wider range of needs of students. They believe that special educators should work with the regular teacher in the classroom to support the student's educational needs. This reinforces Salisbury's view (1991) that inclusion and integration in mainstreaming are two differing approaches (1991). Salisbury (1991) defines integration as placing the child with disabilities in a class with other children. Inclusive programs attempt to meet the needs of all children in the program, with less stress being placed upon the special education placement and more on the needs of all children. In determining the most appropriate learning environment for a child with albinism, just as with any child who has a visual disability, "all options from a complete array of placement options must be considered by educational teams after which a decision is made as to the environment which will provide a student full access to quality educational services based on his or her individual needs" (Huebner & Koenig, 1990, p. 11). Nonclassroom support personnel such as physical education, music, and art teachers need to be informed of the visual disabilities involving students with albinism (Dempsey & Wharton, 1988). Often, it seems that the special subject teachers are neglected when information is disseminated concerning children with disabilities. Yet by utilizing the skills of all special area teachers, the program for special needs students can be enhanced (Greer, 1992). The special teacher of the visually handicapped students must handle the demands of regular teachers as well as stresses which are related to their specialized area of education (Bina, 1982), and integrate all areas of the curriculum for the benefit of the child.

Parents of handicapped children often have more information and involvement in the schools than those of regular, non-handicapped children,

because the special education teachers are intensely involved in reporting to parents of events which have occurred during the year and counseling parents during the duration of the child's school career (White & Calhoun, 1987). Parents can be vital in maintaining positive lines of communication with their child's teacher, and actually increase communication and teacher morale by recognizing the teacher's efforts (Bina, 1982).

According to Gail M. Summer, M.D. (1991), it is possible to straighten the strabismus of persons with albinism through surgery. However, she points out that this will improve alignment of the eyes, visual field, and appearance, but will not provide excellent binocular function in vision.

Curricular adaptations or changes for the student with albinism should be considered during annual revisions of the child's IEP (Bryan, 1989; Morris, 1981; Olson, 1983). According to Turner, Snart, and McCarthy (1992), full integration into the educational program "implies modification of instructional formats, curriculum design, evaluation, and teaching techniques" (p. 34). The IEP should indicate the services needed by a child with a visual disability (Lubke & Corn, 1983).

Orientation and mobility training can be valuable in the educational program of students with albinism. One adult with albinism reported in a journal that she found the training very useful in becoming able to use public transportation independently (Ryan, 1991). Low vision O and M (orientation and mobility) services for preschool children are a new aspect of the field of education of the visually impaired (Bosbach, 1988; Bryan, 1988; Foy, Von Scheden, & Waiculonis, 1992; Pogrund & Rosen, 1989). Utilization of adaptive devices can aid a low vision child to explore the environment safely in a pre-mobility training environment (Hill, Rosen, Correa, & Langley, 1984). There is a severe shortage of specialists trained in orientation and mobility; there is an even greater shortage of

those specialists who are trained in working with low vision preschoolers (Bryan, 1989; Foy, Von Scheden, & Waiculonis, 1992, Joffee, 1988; Lighthouse, n.d.); utilization of an orientation and mobility assistant might be considered to supplement less frequent sessions with the O and M specialist (Wiener, 1990).

Listening skills should be stressed from early childhood, and continued throughout the child's school career (Gleason, 1984). Daugherty (1974) notes that during the period from late elementary school throughout high school and college, the student must "process the bulk of educational material utilizing formal textbooks, a period where extensive reading is crucial to the sighted child. This period requires the student to cope with reading and study assignments which involve a variety of interpretive and organizational skills" (p. 363). Emphasis on listening skills will enable a student with albinism to maximize the effectiveness of use of recorded lessons and tapes of books. During the early 1990s, there has been nation-wide discussion of the merit of braille for all legally blind children. Legal blindness covers a wide variation of impairments, from moderate to severe (Bailey, 1991; Olson, 1983). The low vision population constitutes approximately 80% to 90% of the population of legally blind visually handicapped (Corn & Coatney, 1984).

According to a position paper presented by the Division for the Visually Handicapped, Council for Exceptional Children, "there can be no predetermined reading medium for all students within an arbitrary category and still uphold the principle of educating each student according to his or her individual capabilities and needs" (Koenig et al., p. 10). "To prevent a child from learning to read in print who has the capability to do so is indeed a barrier to achieving literacy" (Koenig et al., 1990, p. 10). "Each student with a visual handicap should be assured that decisions regarding the reading medium are based on observed sensory functioning and not on arbitrary criteria such as the student's visual

acuity or legal definitions of visual handicaps" (Koenig et al., 1990, p. 11).

According to Corn (1983), most modern educators who work with low vision students maintain that visual function assessments should be utilized rather than clinical measures of acuity in determining the appropriate educational needs of the individual child. Students with low vision frequently are lacking basic concepts and unable to integrate components of the environment (Bailey & Hall, 1990). Special efforts must be made to teach these concepts in order to help the visually handicapped student have a knowledge base as similar to that of the sighted peers as possible.

Optical devices will not correct vision which is severely limited, but they can allow the child to make the best use of their visual functioning (Gardner & Corn, 1990). "Optical devices, sometimes referred to as low vision devices, consist of one or more lenses placed between the eye and the object to be viewed. Such devices are designed to maximize the visual abilities of individuals by altering the size and/or the position of the 'projection' of an object on the retina" (Gardner & Corn, 1990, p. 12). Simple magnifiers often work quite well (Brilliant, 1983). An expensive low vision device is not always the best aid for a child with albinism. According to Gardner & Corn (1990), "the sophistication of a device does not necessarily correspond with its usefulness" (p. 13).

Years ago, sight-saving classes were common and use of vision was discouraged. Research has shown that "use of impaired vision does not lead to any deleterious ocular effects" (Gardner & Corn, 1990, p. 13). By using optical devices and low vision devices, the student can achieve greater access to the visual environment. Often enlargements provided for low vision students are available only in black and white. In an effort to increase access to color enlargements, Muranaka, Furuta, Aoki, and Gohke (1985) utilized a modified color video magnifier to make printed materials and illustrations more readily

and attractively available to low vision students.

The decision as to use of a low vision device or use of standard print at a close distance should be made according to the preference of the individual student. According to Gardner & Corn (1990), large print at a typical reading distance of 10 to 14 inches and use of regular print within three to six inches of the eye both present the same size of image upon the retina. Providing children with large print as the only reading medium when the child is able to use a low vision device for reading purposes is actually restricting the visual environment for that child (Corn & Koenig, 1991). Corn and Koenig (1991) cited five studies which indicated that there are few, if any, advantages to using large print if the child is able to use regular print with the aid of an optical device.

Although the low vision optical devices may be initially expensive, the cost may be justified in the long run because of the high cost of texts in large print. The average cost of large type books in their study was an average of $140.00 per text. Nearly half of the students in the study used five or more textbooks annually. Large print texts are difficult to obtain, size of print is not standardized, and illustrations are in black and white instead of color. According to Corn and Koenig (1990), educators have an obligation if they are striving to meet the concept of least restrictive environment to encourage all children who can use optical aids effectively to use these aids. The freedom which the child receives by having the ability to use "regular print at near, intermediate, and distance levels, as well as with the sense of visual control and self-sufficiency that comes with the efficient use of optical devices" (Corn and Koenig, 1990, p. 13) is a worthwhile goal and very appropriate for children with albinism.

According to Koenig and Ross (1991), in determining the appropriate medium for reading for a visually impaired child, if the decision has been made that the child should be a print reader the next step should be to determine if the

child should read regular print, large print, or regular print with a low vision device. In determining the effectiveness of the use of a low vision device, Koenig and Ross (1991) caution that the educator must be certain that the student has mastered the use of the device so that a valid determination of the effectiveness can be made.

Children with albinism are able to use low vision devices with great effectiveness (Efron, 1990; Haefemeyer, King & LeRoy, 1986). Use of low vision devices as opposed to exclusive use of large print has several advantages, according to Koenig and Ross (1991). As the student progresses to higher grades, the print used in texts becomes smaller. The students's visual functioning may also change over a period of years. Low vision devices are improved and invented annually, so the assessment for use of low vision devices should be an ongoing process during the student's school career (Koenig & Ross, 1991).

Use of low vision devices with babies and preschoolers is a controversial issue (O'Donnell & Livingston, 1991). Advocates of early introduction of the optical aids note that if children are accustomed to the devices in early childhood, they are more ready and willing to utilize the devices in older years (Corn, 1980). However, approximately one half of low vision clinics do not serve preschoolers, and school age children are not served in nearly 20% of the clinics (Kirchner, 1985). Most low vision clinics serve an adult population (Lawrence, 1985). Specialized instruction in reading with any reading medium will be necessary in order for the low vision student to have the opportunity to attain a reading rate comparable to sighted students (Fridal, Jansen, & Klindt, 1981).

Description of the Solution

The writer surveyed 20 teachers of visually handicapped students to determine practical strategies which have worked with children with albinism.

One hundred seven adults with albinism and/or parents of children with albinism were surveyed to determine strategies which have been beneficial to students with albinism.

Contact was made on an international level via the American and European support organizations for this condition. The organizations which assisted with this practicum consisted of three separate organizations working with visually impaired individuals, the first a national support group (United States) for individuals with albinism, the second was an international organization dealing with albinism, and the third was a national (United States) parent group which deals with visually impaired children birth through adulthood. Membership was multiracial, and spanned a broad range of backgrounds and professional interests.

The writer devised a booklet which details tips for teachers of children with albinism. This booklet was published jointly by the National Association for Parents of the Visually Impaired and the National Organization for Albinism and Hypopigmentation. This enabled the booklet to be made available and publicized nationally. The booklet was distributed through the two major support organizations, National Organization for Albinism and Hypopigmentation (NOAH) and National Association Parents of the Visually Impaired (NAPVI). There is so little information currently available on the condition of albinism that this was evaluated as a valuable aid for the professionals and for parents.

In the past, booklets with general tips for teachers of visually handicapped students have been utilized by teachers. These booklets have been excellent as a general approach to the entire spectrum of visually impaired children in educational settings. The solution strategy devised in this practicum was the first time a booklet specifically geared for strategies for children with the condition of albinism would have been devised.

The president of National Organization for Albinism and Hypopigmentation, the national support organization, indicated that the booklet would be of great help to teachers throughout the United States. The president of National Association for Parents of the Visually Impaired (NAPVI) agreed that the booklet would be useful and NAPVI indicated a willingness to publish the booklet and distribute it through their national and international contacts. During the implementation of this practicum, the writer was asked by the national organization to consider developing a brochure or booklet designed specifically for the needs of infants and preschoolers with albinism. The writer developed The Very Young Child with Albinism (see Appendix I). The booklet was evaluated by teachers working in a summer preschool daycare program where a child with albinism was enrolled.

Report of Action Taken

Prior to the implementation of this practicum, the writer contacted the national and European support organizations for the purpose of sharing the ideas for the practicum and obtaining suggestions and approval.

During the first month, contact was made with the American and European support organizations to obtain approval for access to their membership. The writer contacted teachers of the visually handicapped to determine techniques which have been successfully used with children with albinism.

During the second month, letters were mailed to individuals with albinism asking for their participation. The major support organizations provided the writer with their mailing lists, permitting the writer to establish contact with individuals throughout the United States, Canada, and Europe. A database of participants was established. Letters were sent to families of children with albinism and to teachers of the visually handicapped asking for volunteers to

participate in the study. Teachers were selected on a volunteer basis from the Southeastern region of the United States. Parents were volunteers from across the United States and Canada. A group of fifty international members of the Albino Fellowship were contacted in a random sample. International members who consented to participate in the practicum included individuals living in Austria, Australia, Canada, England, Egypt, France, Germany, Holland, Ireland, Italy, Jordan, Kuwait, New Zealand, Nigeria, Northern Ireland, Portugal, Saudi Arabia, Scotland, South Africa, Spain, Tasmania, and Tanzania.

During the second month, the writer began writing the manuscript for the educational booklet, tentatively titled When You Have a Child with Albinism in Your Classroom: Suggestions for Teachers, based upon input from the teachers and other individuals. A specialized booklet was devised which could be used by parents or teachers in learning of some of the unique visual implications involved in educating a child with the low vision condition of albinism. This booklet was reviewed by the President, the Board Member/Education Consultant, and nationally- recognized member of the Board of Scientific Advisors of National Organization for Albinism and Hypopigmentation, and suggestions given. Numerous revisions were made in order to include the suggestions.

The manuscript was submitted to the National Organization for Albinism and Hypopigmentation and to the National Association Parents of the Visually Impaired for consideration for publication. The writer was able to utilize a binding system to place the booklet in a more professionally appearing format for submission.

During the third and fourth month, revisions on the booklet were made after review by educational consultants, NOAH board members, and teachers. Preliminary responses from international participants were entered into a database. During the fourth month (mid-point of implementation), the writer

notified the American and European support organizations of the progress to date. An educational consultant represented the writer at meetings and discussions during the board meetings. The meetings of the NOAH board are held in Philadelphia, Pennsylvania, and the writer was unable to attend personally. Contact with the board was maintained through correspondance and through telephone contact. Responses from international participants continued to be recorded.

The writer was able to sumbit the manuscript to the printer camera ready through use of a word processing progam, a Macintosh LC computer and Apple Personal LaserWriter printer. This saved the organizations approximately $500.00 on typesetting fees alone. The booklets were published by the national organizations and are being sold by the organizations for fundraising purposes. The writer had distributed the manuscript version of the booklet to a separate participant pool of teachers of the visually handicapped for their preliminary assessment. The writer obtained copies of the booklet for a nominal fee for use with the evaluation by parents, teachers, and international participants.

The booklet was copyrighted in two forms through the U. S. Copyright Office of the Library of Congress. The writer obtained a copyright for the original individually bound manuscript edition which was submitted for publication (see Appendix G), and a copyright was later obtained for the revised published edition (see Appendix H). Copyright protection is a relatively simple procedure. Two copies of the work must be sent to the Copyright Office along with a twenty dollar registration fee and the application papers. Federal guidelines require that the material must be sent within three months of publication, and provides the bearer to U. S. and international copyright protection. Initial copyright for the individually bound issue was obtained by the writer in her own name; copyright for the final published edition of the booklet was assigned by the writer to the two

national organizations.

Parents and teachers were asked to volunteer to be contacted after the implementation period to determine the effectiveness of the booklet and assess its application to the child's educational program. Of the 135 parents who originally agreed to participate in the practicum, 107 returned the evaluation forms. All 20 teachers participating returned forms. Of the fifty international participants, 41 returned evlaution forms.

Beginning in the fourth month, the writer was able to maintain contact with other educators of children with visual disabilities via an experimental bulletin board service developed through the writer's state department of education. The "VH Exchange" allowed access to parents, educators, social workers, university personnel, and education department members. All were able to communicate state-wide on a wide range of needs. One teacher contacted the writer for specific assistance in the area of albinism, and the booklet devised in the strategy was publicized throughout the state. Due to this BBS posting, requests for the writer's booklet were received from teachers across the state. Copies were made available for parents and educators through the state Commission for the Blind.

During the fifth through sixth months, the writer contacted participants to obtain preliminary assessment of the value of the booklet to date and note any suggestions for revisions. The participants indicated that the booklet was suitable without any further major revisions. During the fifth month, the writer conferred with state university personnel preparation educators and made the booklet available for use by future educators of children with visual disabilities. The writer met with school teachers in nearby school districts to provide support and information. As an outreach activity, the writer assisted a parent group in taking a group of children with visual disabilities, including a child with albinism, to the

circus. Assistance was provided in assuring the optimal visual experience for the children.

During this time, the writer was asked by a national leader to consider the possibility of developing a booklet specifically for the needs of infants, toddlers, and preschoolers with the condition of albinism. The writer agreed to develop such a booklet (see Appendix I) and used it with a summer preschool program which included a child with albinism. Other activities during the sixth month included presentation of the school-age student booklet and discussion of the aspects covered with a pediatric opthalmologist, conferences with local school administrators on low vision adaptations for students, conferences with parents concerning IEP needs of children, a visit to a school, located in a neighboring state, which fully integrated technology into the school curriculum and enabled students with disabilities to be served in-class rather than be "pulled out," electronic conferences with an advocate for the World Blind Union, and sharing of a videotape of animals with albinism to preschoolers and primary age children. The writer was asked to assist a preschool in the region to establish a summer program for children with visual disabilities, including a child with albinism.

During the seventh month, the writer provided a workshop for parents who needed assistance in IEP development (see Appendix J). The writer also during the month provided telephone conferences for parents on Monday through Friday evenings from 7 pm until 9 pm. Parents were able to ask specific questions dealing with their child's individual needs in preparation for school IEP meetings. The writer met with individuals who would be assisting with the summer preschool program in the following month. Specialists in art, music, crafts, storytelling, and including individuals experienced in work with low vision children were involved in the activities. Coordinated plans were developed for providing play activities which could enhance learning and interaction with

normally sighted children. During the seventh and eighth months of implementation, an outreach activity was conducted which involved taking two visually impaired preschoolers (one four year old with albinism and a five year old with visual limitations due to fetal alcohol syndrome) to a Red Cross swimming program for a two week period. The children also played in a 20-inch deep pool during the day for practicing skills learned in the Red Cross lessons.

During the eighth month of implementation, the preschool program was implemented in the private school. Two children with visual disabilities (one 4-year old with ocular albinism and one 5-year-old with cortical visual impairment) and a small group of normally sighted children, all 4- & 5-years old, were provided with a wide range of activities two days each week. Music, art, crafts, reading, storytelling, and field trips were included in the month-long program. Field trips to a farm to see cows and to a horse ranch for feeding horses, riding astride a saddled horse, and riding in a horse-drawn buggy were provided for the children. The children were able to play with a miniature horse and learn basic elements of horse care through instruction from a local horsebreeder. The children with visual disabilities were integrated into the regular preschool program to participate with all children in the preschool. The teachers who were on staff were provided with inservice training and the preschool booklet (see Appendix I). The writer has agreed to provide consultation services for the program in the 1992-1993 school year.

At the end of the eighth month, data was collected and assessed to determine the effectiveness of the program, and the implementation period came to an end.

CHAPTER V

RESULTS, CONCLUSIONS, AND RECOMMENDATIONS

The primary goals of this practicum were to devise strategies which would assist teachers of children with albinism to better serve their educational needs and to make these strategies available in the United States, Canada, United Kingdom, and international community.

An analysis of the results follows, and anecdotal information is included in the conclusion of this chapter.

Results

Outcome 1 -- Teachers of children with albinism will indicate an increase in understanding of the program needs of these students. This was to be assessed by a survey of 20 teachers who had agreed to participate in a follow-up procedure at the end of the eight month implementation period. These teachers were volunteers and all specialists in education of the visually handicapped. There was agreement among all 20 teachers who evaluated the

booklet that the booklet would increase understanding of the needs of children with albinism. This outcome was met.

Teachers were provided with a short evaluation form to assess their perceptions of the booklet designed for school-age students (see Appendix C). The 20 teachers involved in this survey were volunteers who agreed to participate in the practicum project. All 20 responded to the survey. Questions asked and responses gleaned are indicated below:

1. The information provided is appropriate for students with albinism.

    16 Agreed

    4 Strongly Agreed

2. Teachers already have an understanding of the condition of albinism and would not need this information.

    14 Disagreed

    5 Strongly Disagreed

    1 Uncertain

3. This information would help me as a teacher and other teachers to better serve the child's educational needs.

    20 Agreed

This was the only question in the survey which received the same response from all respondents.

4. I wish that I had been able to obtain this information when I first learned my first student with albinism was enrolling in my class.

18 Agreed

2 Strongly Agreed

5. This information will be helpful to medical and social work personnel to assist in explaining the needs of children with albinism.

14 Agreed

6 Strongly Agreed

Several noted that the medical community sometimes fails to consider educational input as important.

Responses to the survey by 20 teachers of students with visual disabilities indicate that Outcome Measure 1 was achieved.

An additional survey was conducted following the conclusion of a private, church-supported preschool program conducted for children with visual disabilities, using the same form which was used with teachers of students with visual disabilities. The five preschool teachers, who were not state-certified educators, had worked with the program as well as working with the preschool during the school year were interviewed and completed the

following survey evaluation of the booklet designed for preschool use (see Appendixes C and I). Results of the evaluations are indicated below

All strongly agreed that the information provided is appropriate for students with albinism. All strongly disagreed with the statement that teachers already have an understanding of the condition of albinism and would not need this information. All strongly agreed with the statement "this information would help me as a teacher and other teachers to better serve the child's educational needs." All indicated that the statement "I wish that I had been able to obtain this information when I first learned my first student with albinism was enrolling in my class was not appropriate for their setting, noting that the child enrolled during the summer program had been their first student with albinism. All strongly agreed that "this information will be helpful to medical and social work personnel to assist in explaining the needs of children with albinism."

The results of this survey indicated clearly that the solution strategy was successfully used with the teachers in the preschool program. These teachers were not state-certified as public school educators, but were preschool daycare workers who had worked successfully in the program for a minimum of three years. The program accepted children with disabilities, but prior to the special component of this practicum teachers had never worked with students with visual disabilities.

Outcome 2 -- Parents will indicate an increase in satisfaction with the teacher's understanding of their child's educational needs. This outcome was assessed through a checklist which was completed by parents at the end of the implementation period. Analysis of the evaluations returned indicated that this outcome was met. Originally, a total of 135 parents volunteered to participate in the follow-up survey; 107 completed the assessment.

1. The information provided is appropriate for students with albinism.

82.9% Agreed

17.8% Strongly Agreed

2. Teachers already have an understanding of the condition of albinism and would not need this information.

89.7% Disagreed

8.4% Strongly Disagreed

1.9% Uncertain

3. This information would help my child's teacher(s) to better serve my child's educational needs.

96.3% Agreed

3.7% Strongly Agreed

4. I wish that I had been able to obtain this information when I first learned of my child's visual disability.

87.9% Strongly Agreed

12.1% Agreed

5. This information will be helpful to medical and social work personnel to assist in explaining the needs of children with albinism.

89.7% Agreed

9.3% Strongly Agreed

0.9% Uncertain

Analysis of the responses indicates that Outcome 2 was met successfully.

Outcome 3-- Individuals with an interest in albinism will be surveyed on an international basis to determine the need of other countries for the information provided in the practicum. These participants were contacted through the membership list of the Albino Fellowship. Fifty members from Austria, Australia, Canada, England, Egypt, France, Germany, Holland, Ireland, Italy, Jordan, Kuwait, New Zealand, Nigeria, Northern Ireland, Portugal, Saudi Arabia, Scotland, South Africa, Spain, Tasmania, and Tanzania were contacted. Of 50 surveys mailed to contacts internationally, 41 were

returned. The names were selected at random from the Albino Fellowship organization mailing list.

A questionnaire was utilized to assess the opinions of international respondents. Results of their responses are as follows.

1. Which best describes your involvement with albinism?

22 Parents of child with Albinism

5 Educators

4 Medical Professionals

7 Adults with albinism

4 Other

(one respondent was both an educator & a parent)

2. Are educational services to visually impaired children in your local schools provided by:

29 Regular teacher

32 Special Teacher of the Visually Impaired

6 Regional Consultant

2 Other

Some respondents selected more than one.

3. Are children with albinism generally accepted by other children or rejected by them?

36 Accepted by other children

2 Rejected

2 Uncertain

1 No response

4. Are visual aids (glasses, magnifiers, spectacles, etc.) provided by the government, local agencies, or privately funded by the family of the child?

19 Fully/partially by governmental source

21 Privately funded

1 No response

5. Do you believe that teachers understand the visual needs of students with albinism?

33 No

6 Yes

2 Partial understanding

Two survey comments specifically mentioned that specialist teachers appeared to have an understanding but that regular classroom teachers did not have such an understanding.

6. Are individuals with albinism in your country usually permitted to operate an automobile?

38 No

2 Yes

1 No response

7. Are materials for students with albinism provided in:

31 Regular Print (including use with low vision devices)

25 Large Print

9 Audio Tape

1 Braille

Many specifically stated that Braille was not appropriate for students with albinism. Many of the participants noted that more than one mode of reading medium is commonly utilized.

Analysis of the responses indicates that Outcome 3 was met successfully. The survey respondents clearly indicated that there was a need for this information in the international community.

Outcome 4 was that a booklet which detailed the educational needs of children with albinism would be developed and made available to parents and teachers on a local, national, and international basis. Acceptance of the booklet by a state, national, or international organization was considered achievement of this outcome. This outcome was met by obtaining approval and acceptance of the writer's booklet by the National Organization for Albinism and Hypopigmentation (NOAH) (see Appendixes I & K), the National Association for Parents of the Visually Impaired (NAPVI) (see Appendix M), the Albino Fellowship of Europe (see Appendix N), the three major national and international organizations which work with children with the condition of albinism. The booklet was published jointly by the National Organization for Albinism and Hypopigmentation (NOAH) and the National Association for Parents of the Visually Impaired (NAPVI). This level of acceptance and approval for the solution strategy utilized in this practicum was considered an honor by the writer. The material in the booklet The Student with Albinism in the Regular Classroom was also used by NOAH for an internationally distributed four page information bulletin on student needs (see Appendix O). The writer has received letters of support for the booklet from the director of children's services (see Appendix P) and from a member of the NOAH Board of Scientific Advisors (see Appendix Q).

Discussion

The goals of the practicum, to devise strategies which would assist teachers of children with albinism to better serve their educational needs and to make these strategies available in the United States and, if appropriate, internationally, were achieved. The response to the practicum was overwhelmingly positive and supportive. Children with albinism do have unique needs which often are not understood by educators, according to both the literature reviewed and the surveys compiled during this practicum. One parent noted that the visual difficulties involved with albinism present a hidden disability which may not be recognized by classroom teachers or parents. Parents as well as educators need to be aware of the needs of the child and need to work in a cooperative effort to ensure that each child receives the appropriate educational opportunities mandated in Federal legislation such as 1990's Individual with Disabilities Education Act.

Recommendations

Although it might be more desirable for a booklet to be published by a larger organization for the purposes of widespread distribution possibilities (as was done in this practicum), in special areas with limited sales potential the

individualized production of materials should be considered. Low incidence special education areas such as albinism have a small number of children in comparison to the total special education population. Parent organizations in other low incidence etiologies could produce materials to aid teachers in understanding the needs of children with particular conditions. By also making the materials available through sources such as the ERIC database, this could be a feasible method of assisting teachers.

The writer utilized an Apple IIgs computer and Apple Works 3.0 software to prepare the manuscript for the booklet for teachers. This material was able to be transferred to a Macintosh format through use of the software Claris Works, by Claris Corporation. Apple Works is also a Claris product, so there was a transfer program for the Apple Works to Claris Works files built into the software. The transfer process was very simple and easy to manage. The material was then printed on a Personal Laser Writer printer in 14 point print, a larger font which can be more easily read by an individual with low vision. The Macintosh computer and Personal Laser Writer printer were used to print the booklet developed in the practicum and permitted the writer to present the manuscript camera ready to the printer for the national organizations. This gave an initial savings of $500.00 on the cost of publication, because the printer's fee for typesetting was $25.00 per page. It is strongly recommended that any group which considers developing a booklet for their own needs consider use of the Macintosh computer and Laser Writer printer for printing the material. Apple computers are found in most schools

and can be used to type the manuscript, if Macintosh computers are not readily available. The document can then be easily transferred to the Macintosh, and the writer strongly recommends use of Claris Works software. The final product is a professionally appearing publication. The system and the Claris Works software were very easy for use by computer non-experts. Any questions regarding the software utilization were answered by customer service representatives of Claris Corporation through telephone contact. These representatives were friendly and supportive, and gave the writer a very positive impression of the company.

The writer was assisted by the Supervisor of Children's Services for the South Carolina Commission for the Blind in compiling a list of materials which should be included in a program for students with visual disabilities. These materials are appropriate for a wide spectrum of visual disabilities.

General items would include desks with adjustable surfaces that can tilt for better angle or allow for wheelchair accessibility, adjustable height chairs, white marker board with matte finish, storage cabinets and carts for students to use for carrying Braille/ large print materials from class to class, incandescent and halogen lights, electric typewriters (large print and regular print), computers (Apple II, IBM, and Macintosh), Close-Circuit TV systems (CCTV)--at least 2 in a resource room and 4 for classrooms), an assortment of

handheld aids, independent living aids, canes, audio and video taping and playback equipment such as cameras, cassettes, and duplicating machines, contrasting surfaces for tabletops, stairs, doorways, etc., and a small dark room for vision stimulation.

A van with desktop and storage capacity, electrical hookups and a travel budget would allow for both in-school and field trip travel. The van could double as a mobile classroom. Disability specific items would include Braille computer keyboards, expanded keyboards, touch pads and windows, switch and switch components for equipment and toys. Speech synthesis is available through use of computers. Braille machines for individual student use can be supplemented by Braille based computer systems such as the Navigator. Versa-point Braille embossers are compatible with Apple II, Macintosh, and IBM compatible computers. The Kurzweil Personal Reader by Xerox (currently costing approximately $12,000) allows print materials to be scanned and output by speech synthesis. Large print displays for computers would be very helpful to students with albinism.

Large print computer software, useful for students with albinism, can include: Dr. Peet's Talk writer ($60), Close View (for the Mac), InFocus ($295), InLarge ($95),Hyperscreen ($125), I Can Write! ($60), Handy view ($195), LVE (Low Vision Editor ($20), Lyon Large Print program ($850), Large Print DOS ($495), Large Print DOS Deluxe Edition with L-Picasso ($650), and Rebus Writer ($50). The writer was pleased to discover that the

Macintosh LC computer came with built in software which would enable the screen display to be turned into a large print format. This consideration for the needs of low vision or visually impaired individuals by the Apple Corporation was very impressive.

Dissemination

The booklet developed in this practicum was introduced at the School Nurses Conference at the Wills Eye Institute Annual Conference in Philadelphia, Pennsylvania, on April 4, 1992, by Janice Knuth, president of N.O.A.H.

The information about the availability of the booklet has been shared within the writer's state via an electronic bulletin board system called the VH Exchange, developed by the state department of education and a state university. The writer was one of the first persons authorized to access this system.

The availability of the booklet, The Student with Albinism in the Regular Classroom, was announced in the June, 1992, edition of Journal of Visual Impairment & Blindness (see Appendix R).

The writer is considering submitting a proposal to present the findings and results of this practicum at the next national Council for Exceptional Children Convention, in Tucson, Arizona, in 1993. The writer also plans to

write a journal article based upon the results of the practicum and submit to a journal for teachers of students with visual disabilities.

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APPENDIX A

BIBLIOGRAPHY OF MEDICAL ARTICLES ABOUT ALBINISM

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ARTICLES ABOUT ALBINISM

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APPENDIX B

LETTER TO TEACHERS

1032 Trail Road
Belton, SC 29627

Dear Teacher,

I am a graduate student in the Ed.D. Program in Early and Middle Childhood at Nova University. This survey is an attempt to determine appropriate educational interventions which have been effective with students with the etiology of ocular albinism or oculocutaneous albinism.

The nature of the project is to survey the opinions of teachers of children with albinism in regard to educational techniques. Participation involves filling in the enclosed questionnaire. The results of this study will provide teachers of children with albinism with more information on the condition and on educational procedures which will help the children be as successful in school as possible. The information will also benefit parents and support workers in understanding how albinism affects a child's school work.

Your participation is completely voluntary. Information on this questionnaire will be anonymous and held in strict confidence. Only group results will be reported. If you have any questions, please call Julia Ashley at (803) 338-9593.

If you would like to receive results of this research, please return this letter with your name & address. I appreciate your completion of this questionnaire.

Sincerely,

Julia Ashley

I would like to receive summary results:

Name:

Address:

APPENDIX C

EDUCATOR CHECKLIST

EDUCATOR CHECKLIST

Please fill out the following checklist items after reviewing this booklet. Give any additional comments you feel appropriate. Return to Julia Ashley in the enclosed self-addressed envelope (no postage required). Thank you very much for your help and support in this project.

SCALE

5 = Strongly Agree
4 = Agree
3 = Uncertain or Undecided
2 = Disagree
1 = Strongly Disagree
NA= Not Applicable

1. The information provided is appropriate for students with albinism.
5 4 3 2 1 NA

2. Teachers already have an understanding of the condition of albinism and would not need this information.
5 4 3 2 1 NA

3. This information would help me as a teacher and other teachers to better serve the child's educational needs.
5 4 3 2 1 NA

4. I wish that I had been able to obtain this information when I first learned my first student with albinism was enrolling in my class.
5 4 3 2 1 NA

5. This information will be helpful to medical and social work personnel to assist in explaining the needs of children with albinism.
5 4 3 2 1 NA

APPENDIX D

CHECKLIST FOR NON-EDUCATORS

Please fill out the following checklist items after reviewing this booklet. Give any additional comments you feel appropriate. Return to Julia Ashley in the enclosed self-addressed envelope (no postage required). Thank you very much for your help and support in this project.

SCALE

5 = Strongly Agree
4 = Agree
3 = Uncertain or Undecided
2 = Disagree
1 = Strongly Disagree
NA= Not Applicable

1. The information provided is appropriate for students with albinism.

5 4 3 2 1 NA

2. Teachers already have an understanding of the condition of albinism and would not need this information.

5 4 3 2 1 NA

3. This information would help my child's teacher(s) to better serve my child's educational needs.

5 4 3 2 1 NA

4. I wish that I had been able to obtain this information when I first learned of my child's visual disability.

5 4 3 2 1 NA

5. This information will be helpful to medical and social work personnel to assist in explaining the needs of children with albinism.

5 4 3 2 1 NA

APPENDIX E

Checklist Completed by

Albino Fellowship Participants

1. Which best describes your involvement with albinism?

__Parent of Albino __Educator __Medical Professional __Albino __Other

2. Are educational services to visually impaired children in your local schools provided by:

____ Regular teacher ____ Special Teacher of the Visually Impaired

____ Regional Consultant ____ Other (explain)

3. Are children with albinism generally accepted by other children or rejected by them?

4. Are visual aids (glasses, magnifiers, spectacles, etc.) provided by the government, local agencies, or privately funded by the family of the child?

5. Do you believe that teachers understand the visual needs of students with albinism?

6. Are individuals with albinism in your country usually able to operate an automobile? ___ yes ___ no

What is the usual means of transportation for them?

7. Are materials for students with albinism provided in:

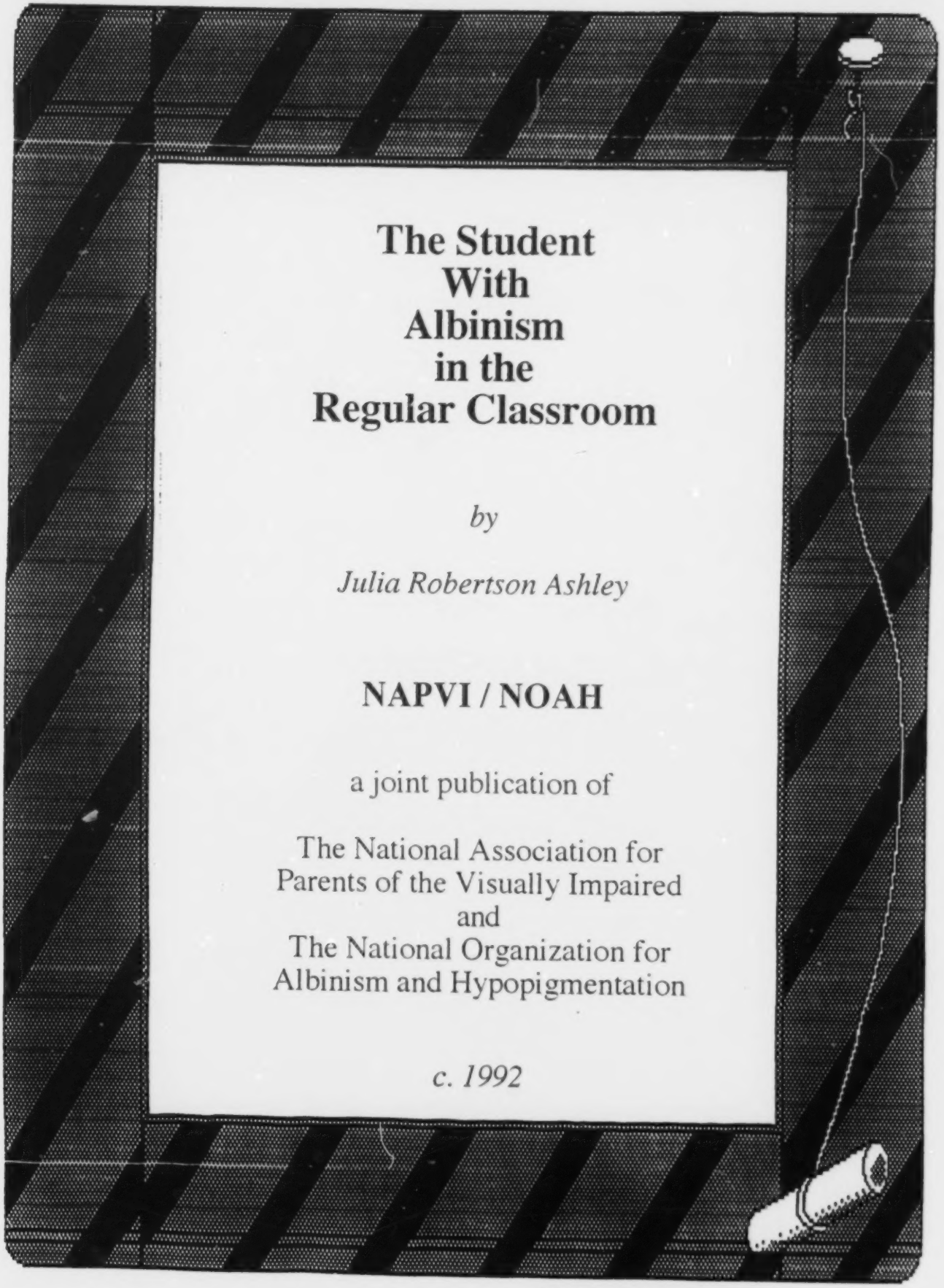
____ large print ____ Braille ____ Auditory Tape

_____ regular print (may be more than one)

APPENDIX F

BOOKLET:

"THE STUDENT WITH ALBINISM IN THE REGULAR CLASSROOM"



The Student With Albinism in the Regular Classroom

by

Julia Robertson Ashley

NAPVI / NOAH

a joint publication of

The National Association for
Parents of the Visually Impaired
and
The National Organization for
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c. 1992

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Julia Robertson Ashley is a teacher in Anderson Co. (S.C.) School District Two, and a student in the Ed.D. Program in Early and Middle Childhood at Nova University, Ft. Lauderdale, Florida. This booklet was developed as part of the author's major practicum in the Ed.D. program. Information contained herein was derived from research conducted as part of the author's coursework in the Master's Degree program in the Program for Exceptional Children: Visually Handicapped at the University of South Carolina and in the doctoral program in Early and Middle Childhood Education at Nova University. Mrs. Ashley, the 1991 Outstanding Student of the Year (Division for the Visually Handicapped/Council for Exceptional Children), has 18 years experience in teaching and is certified in Special Education Visually Handicapped, Media, English, and Social Studies. She is the mother of a child with albinism.

ACKNOWLEDGEMENTS

The author acknowledges with gratitude the invaluable guidance and counsel of the National Organization for Albinism and Hypopigmentation (NOAH), the Albino Fellowship, and the National Association for Parents of Visually Impaired (NAPVI). The suggestions and recommendations included in this booklet have been reviewed by these organizations. Appreciation is also expressed to Mrs. Elizabeth McCown and Mrs. Judy Warco of the South Carolina Commision for the Blind, to Dr. Polly Peterson and Dr. Mary Ellen Sapp, who were the advisers of the author's major practicum in the Ed.D. Program in Early and Middle Childhood at Nova University, and to Dr. Anne L. Corn, of the University of Texas at Austin, who was able to give guidance and advice based upon personal as well as professional experience.

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PREFACE

Children with albinism have some very special needs in the classroom and elsewhere in the school because of their low vision, sensitivity to bright light, and tendency to sunburn easily. With understanding of their special needs and knowledge of techniques for dealing with them, teachers and other school personnel can help a child with albinism to enjoy school and learn normally. The teacher and other school personnel will, therefore, find working with the child with albinism a rewarding experience. However, without the needed understanding and adaptations, the teacher may be puzzled and frustrated; and the child with albinism will find school a traumatic experience.

Very little has been written specifically about how to help children with albinism in school. We are very grateful to Julia Ashley for writing this booklet. The information in this booklet is based on the author's review of special education literature, a survey, and consultations with leaders of relevant organizations. Her survey was sent to special education teachers as well as members of the National Organization for Albinism and Hypopigmentation (NOAH) in the United States and the Albino Fellowship in Scotland. Respondents to the survey included persons with albinism, parents of children with albinism, and teachers of the visually impaired who have worked with children with albinism. In writing this booklet, the author consulted closely with leaders of NOAH and National Association for Parents of the Visually Impaired (NAPVI).

This booklet begins with an explanation of albinism, then discusses special needs of the student with albinism in the classroom and presents information about adaptations and other methods for responding to these special needs. The author also addresses some of the special social and emotional problems the child with albinism will experience in school and suggests some ways of helping the child with albinism and classmates deal with these. Special considerations related to nonclassroom activities are also discussed. The booklet concludes with a list of references and resources.

While the booklet is addressed primarily to regular teachers in elementary and secondary schools, it is also written for school administrators, school counselors, school nurses, and other school personnel. Others who will find it helpful are parents of children with albinism, physicians who are treating children with albinism, and students in fields related to teaching, special education, and medicine.

Janice L. Knuth, MSW, ACSW
President
National Organization for Albinism and Hypopigmentation

INTRODUCTION

A child with albinism is enrolled in your classroom and you have learned that this child has a serious visual disability. You may be uncertain how his or her needs vary from other children in your class. This booklet has been designed to answer questions and address concerns you may have about this child or student in your class and has been designed to help you, the teacher. Use it in whatever manner suits your needs and teaching styles. It is also strongly recommended that you obtain the booklet When You Have a Visually Handicapped Child in Your Classroom, by Mrs. Iris M. Torres and Dr. Anne L. Corn (American Foundation for the Blind, 1990). This booklet has many excellent suggestions for meeting the needs of children with a wide range of visual disabilities. Many of the suggestions in the AFB booklet will be appropriate for a child with albinism. This booklet is available free of charge for single copies to classroom teachers; call 1-800-AFB-LIND to request a copy. You may also wish to request a copy of the latest AFB catalog of publications for additional resources.

Legislation such as the Individuals with Disabilities Education Act and the Americans with Disabilities Act in the 1990s have expanded and updated the provisions of the landmark PL 94-142 (Education of All Handicapped Children Act). These laws have presented teachers with both the opportunity and the responsibility of providing an appropriate education for students with visual disabilities in as least restrictive an environment as possible. Most regular classroom teachers have little or no experience with children with visual disabilities. To be told that you will have a child who is legally blind (as many children with albinism are) can be initially intimidating. Children with albinism have useful amounts of vision for reading and learning and may need to learn alternative approaches to use their vision effectively. This booklet is designed to help you realize that children with albinism have a great deal of functional vision, and just need guidance and opportunities to adapt to regular classroom instruction. In order to help meet the special needs of this child, your school should have support from a special teacher of students with visual disabilities. This teacher has special preparation in the educational needs of children with a variety of ocular conditions, and can help you modify classroom procedures as may be needed. Make a note of any questions you have during the year, and talk to this specialist. The teacher may be a VH (visually handicapped) resource room teacher, an itinerant teacher, or a consultant, depending on the needs of your school. You and your specialist teacher can work together to provide an environment that is stimulating and appropriate for this child's needs. Good luck and best wishes for the school year!

WHAT IS ALBINISM?

Albinism is any congenital hypopigmentation (lack of pigmentation), which can occur in plants, animals, and humans. In the human being, it affects the eye in the form of reduced visual acuity and nystagmus, and causes moderate to serious visual impairment. It has been recorded in earliest history, with speculation that Noah of Biblical fame had albinism (Sorsby, 1958). Most people have seen individuals with extremely fair skin and hair, and may have been told that a person was an "albino". Yet few people in the general public realize that all persons with albinism also have a serious visual disability. This condition is inherited through recessive genes. This means that both parents must carry the same rare gene for a particular type of albinism. It is possible for several children in a family to have albinism, but there is only a 25% chance of any one pregnancy resulting in a child having the condition (Haefemeyer, 1986). The condition is found in approximately one out of every 17,000 people in the United States. Even with the limitations of low vision, individuals with albinism can live normal lives when they have appropriate support and resources. As adults, they have families and jobs and participate in community activities.

Common characteristics of individuals with albinism include nystagmus, strabismus, photophobia, a lack of depth perception, and skin which is extremely easily sunburned. Nystagmus is the involuntary rapid horizontal movement of the eyes, which causes a reduction of visual acuity. Strabismus is the lack of coordination between the two eyes (they don't appear "straight"). There also is a lack of depth perception. The student will have great difficulty in judging distances and spatial concepts but can often compensate for these difficulties. Photophobia is an extreme sensitivity to light which can cause reduced acuity in vision.

THE CHILD WITH ALBINISM IN CLASS

Treat the child with albinism as you would any other. Don't feel awkward using terms such as "look" or "see"--these are normal parts of this child's vocabulary, too. Sometimes teachers worry that they may say the "wrong" word or phrase around a child with a disability. A student who is classified as legally blind or visually disabled still may have a great deal of useful vision for educational purposes (Bailey and Hall, 1990). Don't let the terminology make you uncomfortable. The child knows if he or she is loved and accepted, and won't resent a teacher asking questions. It's OK to ask the child to look and describe what he sees. This may be the most practical way

you as a teacher may have of finding out what his visual field or functional level may be. An excellent source for quickly assessing distant and near visual acuities is the Efron Visual Screening Test (1980), a set of cards which can be used with children from about age three and with non-English speaking persons of any age, and can be administered by the special teacher of the students with visual disabilities. It is an excellent screening test utilizing cards and wall charts. The test distance is ten feet, but acuity measures are reported in standard Snellen-type (20/20, etc.) numbers. One major advantage of this test is that it is able to report acuities falling within the 20/100 and 20/200 range.

Years ago, students with visual problems who were not functionally blind were called "partially sighted". The current accepted educational terminology is "low vision". Low vision is insufficient vision to be able to do a desired task. Low vision children have a serious visual disability, but are able to use their vision for functional purposes, as compared with children who are functionally blind (Barraga and Erin, 1991) and who use other senses as their primary mode for reading and academic learning.

Introduce him or her to the class just as you would with any other new child coming into your class. If other students or teachers have questions, encourage the student with albinism to answer the questions himself or herself. Some children are very open about discussing albinism and others may be less comfortable discussing their condition with classmates. The teacher may wish to discuss possible approaches with the school guidance counselor.

The classroom teacher may have to deal with the element of teasing and namecalling. Children with albinism may have a dramatic physical appearance which could cause other children to tease or say unkind things. Often teasing is a result of the child's not understanding differences. When the children understand another child's disability, the teasing often stops and the other children can become helpful instead of hurtful. Unfortunately, black children with albinism may be subjected to more teasing than Caucasian children with albinism due to the extreme difference in skin pigmentation (Waugh, 1988). Black, Hispanic, and Oriental children with albinism are often misunderstood or rejected by other children, and even adults, of their own race.

One idea to encourage understanding might be to encourage the child with albinism to give a report about albinism and the various devices that are

utilized; however, if a child has been teased, this may be very difficult for him or her to do. This should be suggested, but never required because the child must feel comfortable about this rather than pressured to do so. The classroom teacher will normally help children and their peers to cope with differences; albinism is just one type of a difference. The goal is to develop in children a positive attitude toward differences and to accept others for who they are. Children with albinism are like other children with disabilities in needing help and helping others in developing their self-esteem. Tact must be used, of course. Some children may be inclined to tell the teacher that something is "helping" in order to avoid hurting the teacher's feelings when in fact the child just doesn't know how to tell the teacher that the attempt to help is not working as it is intended.

The child may also have a misunderstanding of how his or her eyes actually look to others. Some children have heard that their eyes move back and forth, and may imagine it to be more serious that it actually appears to others. Dr. Anne Corn suggests having the child place a magnifier on a mirror to allow the child to watch the effects of the nystagmus on his or her own eyes. Dr. Corn related that when she did this with one student, the child said that she didn't think her eyes "looked like that big a deal."

Include this student in all areas of the school program in which any other student would participate. Art, music, physical education (PE), library, and other special activities are appropriate for the child with albinism. The specialist teacher can make suggestions as to modifications which may be needed for these areas (for instance, it would probably be suggested that in outdoor activities during P.E., the student should wear a cap with a visor, sunglasses and a sunscreen. Different games with larger and slower-moving balls may be appropriate).

WHAT DOES LEGALLY BLIND MEAN?

Children with albinism have a wide range of acuities varying from 20/80 to 20/800. You should know the individual student's acuity and functional abilities for the classroom. A typical child with albinism might have an acuity listed as 20/200, which is considered legal blindness. Legal blindness is a term defined by the American Medical Association in 1934 and adopted by the U. S. Congress in 1935 in order to define eligibility for special services for the blind. Legal blindness is defined as "central visual acuity of 20/200 or less in the better eye with corrective glasses or central visual acuity of more than 20/200 if there is a visual field defect in which the

peripheral field is contracted to such an extent that the widest diameter of the visual field subtends an angular distance no greater than 20 degrees in the better eye" (Scholl, 1986, p. 26).

In simpler terms this means that if his or her vision is classified 20/200, the student can see from 20 feet what students with normal vision can see from 200 feet. His near vision (reading distance) may (or may not) be much better; the child might have nearly normal reading abilities if holding a book three or four inches away from his eyes.

Students who are legally blind, as most students with albinism are, will be eligible for quota funds, which can be used to purchase materials from sources such as the American Printing House for the Blind (APH). These materials can be used to supplement instructional materials for the student and are ordered by the special teacher of the visually handicapped. Quota funds are a special allotment provided to school districts (including all legally blind students) by the U. S. government which will aid a school district in obtaining materials for the legally blind students. APH sells books and materials for students with visual disabilities in large print and Braille formats. It maintains a catalog of textbooks available throughout the United States in Braille, large print and recorded formats. The address for APH is: AMERICAN PRINTING HOUSE FOR THE BLIND, 1839 Frankfort Avenue, Louisville, KY 40206. Another source of information is: RECORDINGS FOR THE BLIND, 20 Roszel Road, Princeton, NJ 08540, (800) 221-4792 or (406) 243-5481. This organization merged in the early 1990s with Computerized Books for the Blind to become one organization. The Library of Congress has a catalog entitled Volunteers who Produce Books: Braille, Large Print, Tape. This is a useful source for information on materials which you cannot find in adaptive mediums. Your local library's Reference Department can usually assist you in locating this resource if it is not available in your district. An additional resource you may wish to contact is your state Commission for the Blind or agency for assisting citizens with disabilities. All states have an agency which fulfills this function. Local resources and private agencies should be considered, as well.

DISCIPLINE/CLASSROOM BEHAVIOR AND THE CHILD WITH ALBINISM

You should expect the child with albinism to follow classroom rules and discipline codes just as any other student would. Encourage the student to move quietly about the room as necessary to obtain the best view of activities. If he or she needs to move to another place in order to have a better visual focus on a filmstrip, chart, or chalkboard information, have the child do so independently. The older students often know what works best for them and should be encouraged to learn and use their own methods in compensating for the vision difficulty. The child may need some assistance to know where to stand so as not to block another student's view.

The student with albinism at times might not seem to respond to visual communications and clues from a distance such as the nod of a head indicating a child's turn to answer a question. This is probably because he cannot see them! It may be difficult for this child to recognize facial expressions or hand gestures. Use verbal cues as well as physical ones.

THE VERY YOUNG CHILD WITH ALBINISM

When working with infants and toddlers with albinism, movement activities and learning strategies used with normally sighted preschoolers are appropriate. Outdoor activities should be included, but it is important to make certain that sunshades or sunglasses are utilized with even the smallest children. OshKosh B'gosh makes a train conductors hat in very small sizes which could fit babies of only a few months of age. Another product useful is the sunglass line by Baby Optics. They make sizes including Newborn, Baby, Toddler, and Kid. These have a high UV protection level, are priced under $15.00, and were recommended by a mother who had used them since her child was under one year of age. These products are found at many baby specialty stores. Any use of tinted lenses should be discussed with a parent who should make the decision in consultation with the child's eye specialist.

As the child becomes preschool age, it may be a good idea to gently talk about albinism with the child. Often, other adults may have mentioned his condition around the child thinking that their remarks wouldn't be understood. One mother of a three year old reported her daughter telling her that she had "pink eyes". The mother used crayons to draw pictures of a child with pink eyes and a child with darker colored eyes. The little girl decided herself that she did not have "pink eyes." But "little pitchers have big ears" and the children often may have a misunderstanding of the condition of albinism. According to Dr. Anne L. Corn, Professor at the

University of Texas at Austin, one effective technique to use with a preschooler might be to allow the child to hold a magnifier and talk about Sherlock Hemlock, the detective character on Sesame Street. Dr. Corn recommends beginning as early as age four to introduce children to a monocular (a small, hand-held telescope). This is not to say that the child should be responsible for the monocular and keep it himself, but that parents should show it to the child and allow the child to use it on trips to practice looking more closely at distant objects. If a child is accustomed to using low vision devices at a very early age and realizes the advantages of using them, there is likely to be a reduction of resistance to using them in school, according to Dr. Corn. One parent reported using an inexpensive pair of Big Bird binoculars with a child with albinism who was only two years old. The little girl enjoyed looking through the colorful, low powered binoculars and began to understand the concept of use of visual devices, even though the term "visual devices" were never used. It was just a toy used like any other child which could also pave the way for future understanding.

SCHOOL AGED STUDENTS

Additional desk space may be needed to allow the student to properly use materials such as large print books, low vision devices, magnification stands, or tilted reading stands. The student may bring optical and non-optical devices to class.

Students with albinism are like other children in that they don't want to seem "different" any more than avoidable. If they seem reluctant to use an device such as a monocular (a small, hand-held telescope) or a magnifier, you should discuss this with the special teacher of students with visual disabilities.

Many students with albinism are able to read standard school books in regular print, sometimes with the assistance of low vision devices. The child should be seen by a low vision specialist to determine if optical devices may be useful. If the child needs large print books, these will be obtained by the specialist teacher. If classroom maps or charts are needed, this teacher can often help the regular classroom teacher adapt materials for the student. Large print is often used in elementary grades, but use at school may be discontinued in secondary levels due to the student's desire to use materials like other students. In secondary school, taped books and large print texts are used at home for reading. Regular print books with handheld or stand magnifiers are typically used at school. Tape recordings of texts may be used as well. Auditory devices such as cassettes and tapes may be used to tape lessons and assignments if needed.

The nystagmus and low visual acuity may cause the student to become fatigued during reading; it is important to allow frequent rests during reading periods and written examinations if needed. A rest period need not be long; it may be as simple as having the student look around the room for a few moments. You may need to encourage him to use the adaptive materials and to answer any questions other students might have about their use.

SPECIALIZED INSTRUCTION BY A TEACHER OF STUDENTS WITH VISUAL DISABILITIES

Students with albinism should receive certain specialized instruction to help them compensate for the visual limitations. The special teacher will instruct them in such skills as keyboarding, listening, orientation and mobility (travel and utilization of the environment), and daily living skills. Keyboarding is important because the student can learn to type assignments, reproduce them in large print for review, and write in a less tiring manner. Writing can be a very difficult activity for a student with limited vision. Listening skills are useful for all students, but especially important for a child with a visual disability such as albinism. Often the student will obtain information from teacher lectures and discussions which other students will obtain through vision.

The size of print used with the child will be decided on an individual basis. Braille instruction will not be needed by students with albinism under normal circumstances. The need for an individual evaluation of the need of each child is stated by the Position Paper of the Division for the Visually Handicapped, Council for Exceptional Children, "there can be no predetermined reading medium for all students within an arbitrary category and still uphold the principle of educating each student according to his or her individual capabilities and needs" (Koenig, Sanspree, and Holbrook, 1990, p. 10). "Each student with a visual handicap should be assured that decisions regarding the reading medium are based on observed sensory functioning and not on arbitrary criteria such as the student's visual acuity or legal definitions of visual handicaps" (Koenig, Sanspree, and Holbrook, 1990, p. 11).

Special materials which have been adapted for students with low vision will be ordered by the special teacher for the student. Materials such as large print books, adaptive computer software, and audio tapes will be able to supplement the regular curriculum. The specialist teacher will work with this student to orient him/her to the school building and grounds. The student will be able to see most objects and obstacles within walking

distance. Distant objects and extremely bright areas will be the areas which usually will present most difficulty for a child with albinism.

OPTICAL AND NON OPTICAL DEVICES

The needs of the child with albinism will be met with various optical and non-optical devices. These will be provided by an eye specialist such as an ophthalmologist, optometrist, or low vision specialist or by the specialist teacher.

Bookstands, which will allow the child to bring the reading material closer to his eyes, usually are tilted at an angle, and rest on the student's desk. If the child does not have a bookstand, try putting a large dictionary or several large books under the student's reading material to bring it closer to his face.

Large type books have the same material found in regular school texts, but in larger print. In some states, "large print" may only be 14 point. The legibility of the print is very important. Some large print materials are just magnifications of standard print, and can be quite blurry. Spacing between lines and between letters is an important quality.

Paper which has extra-dark lines, and more space between the lines can make it easier for the student with albinism to write. The teacher may want to experiment with different colored papers to see what works best for the individual child. Often teachers may hear or read the term "preferential" used with visually impaired students. Preferential seating or selection is not based upon a whim or mood; it simply means that the student has certain techniques which visually work best for him or her, and this is the preferred choice for the child.

Students may have special glasses such as bifocals for use in reading. These lenses may be tinted to help reduce glare. A child with an extreme sensitivity to light may wear sunglasses inside as well as outdoors. Children with albinism may have visual acuities fluctuate from day to day. Each child has very unique characteristics, and there is no way to categorize all students with albinism into one visual group.

Telescopic devices such as monoculars may be used to see writing on chalkboards and other distant objects. Monoculars are small, hand-held telescopes which can be adjusted by the student. Binocular glasses, which have telescopes built into the glasses, may also be used for distant viewing of activities such as movies, school plays, or sports events.

MATERIALS FOR READING AND HANDWRITING

It may be desirable to use pens and pencils which are very dark. Materials written with black felt tip pens or black ball point ink are much easier for the student to read than the usual classroom pencils. If a pencil must be used, try to find a #1 pencil, which has a darker colored lead than most classroom pencils.

Acetate sheets, or sheets of colored film or plastic, when placed over a page can make the print or handwritten materials easier to read. The teacher will need to experiment to see what color acetate is best for a particular student.

Handwritten material may be especially difficult for a child with albinism. Tests given to the student should be typed rather than handwritten or written on the chalkboard. Allowing children to trade papers in class and grade one another's papers may place the child with albinism at a disadvantage, because handwritten materials are so difficult to read.

The usual purple ditto masters which many teachers use should probably not be used with a student with albinism. The purple print is virtually impossible for some students to read. Try making a copy of the original material on a copier for this student. The teacher may wish to use a copier which is able to make dark copies for the student, or to enlarge print to make materials more easy to read for the child. Large print versions of many textbooks are available from sources such as the American Printing House for the Blind, but the teacher may have to photocopy and enlarge other materials.

TESTING

Most schools utilize standardized tests during the year. The visually limited student will be able to take these tests, which should be provided in the appropriate medium. Either large print or regular print with use of a low vision device will allow a student with albinism to take the same nationally standardized tests as other children. Some experts believe that these tests should be provided in large print in order to allow the child to mark answers directly in the test booklet. Another school staff member may later transfer the responses to a machine scorable answer sheet. Students with low vision are customarily allowed time and a half to complete such testing, along with visual rest breaks. Some tests allow for extra time for a student with a visual disability. Test-taking can be very visually fatiguing, and a more accurate score will be obtained when the student is given extra time to take the test, and rest breaks.

PHOTOPHOBIA AND GLARE

Children with albinism usually have photophobia, which is an extreme sensitivity to light, and the teacher should seat the child away from windows and glaring light. If the child is seated in the first row opposite windows, he may get too much glare due to reflected light. The child's vision may fluctuate from day to day, and can be affected by fatigue, emotions, and medication.

Glare is a distinct problem for children with albinism. Visors or eye shields may be useful in reducing overhead light and glare. The teacher should take care not to stand with his or her back to the window in the classroom. The glare from the window makes it difficult for the child with albinism to look at the teacher. It is normally difficult for a child with albinism to maintain eye contact; to attempt to do so with glare compounding the condition is virtually impossible. The child will need to be shielded from uncomfortable light which makes his vision even worse.

Special materials which have been adapted for students with low vision will be ordered by the special teacher for the student. Materials such as large print books, adaptive computer software, and audio tapes will be able to supplement the regular curriculum. The specialist teacher will work with this student to orient him/her to the school building and grounds. The student will be able to see most objects and obstacles within walking distance. Distant objects and extremely bright areas will be the areas which usually will present most difficulty for a child with albinism.

NONCLASSROOM ACTIVITIES

Your student with albinism will be able to participate in most activities with only minor modifications, but special consideration should be given to certain matters of safety.

Assembly or Group Presentations -- Most schools allow the youngest children to sit near the front, and the older classes in the rear of the lunchroom, auditorium, or similar area. The student with albinism may need to sit closer to the stage or to use a monocular in order to see adequately. Allowing a friend to sit with the child will make this more enjoyable, especially if the student will be sitting next to much younger children. Do not insist that the child move closer if he or she prefers to remain with classmates.

Field Trips -- Consider informing staff members at museums or theaters that you have a student with a visual disability. If they are informed in advance, special arrangements can often be made to allow the student to get a closer look or even touch some exhibits. In unfamiliar surroundings a child with low vision is at a greater disadvantage, so alert the adult to whom the child's group is assigned.

Physical Education Classes and Outdoor Classes -- Outdoor activities may be difficult for the child with albinism. Physical education classes which involve sports like softball or basketball may cause difficulty for these students, due to the visual problem. Other sports such as track, swimming, and aerobics can be enjoyable for the child with albinism, and they can perform well in these areas. The photophobia may cause discomfort for outdoor activities, but use of ball caps, eye shades, tinted lenses, and sunscreens can help the child enjoy outdoor activities. However, Janice Knuth, President of N.O.A.H. (National Organization for Albinism and Hypopigmentation) pointed out that there is a trade-off in using tinted lenses--tint reduces discomfort from glare, but it also reduces clarity and detail. People with albinism may resist using sunglasses at times because they feel they do not see as well when wearing sunglasses.

Outdoor games played in shade with well-defined boundaries for movement games work well. Children may feel unsure of playground equipment such as slides because of the glare, but enjoy the equipment when they have partners. Yellow balls and colored bases make ball games more visible for the child with albinism. Small ball games (tennis, badmitten, softball, baseball) are extremely difficult for children with albinism, due to both the size and speed of the balls; games involving larger balls work much better. Swimming, aerobics, gymnastics, track, horsemanship, skiing are sports which can be enjoyed with minimal adaptations required.

Fire Drills -- Do not ask another student to assist the child with albinism during drills or actual fires. The visually limited student may need assistance during an emergency, and children can panic or forget in these situations. It is unrealistic and unfair to expect another child to take the responsibility for a peer. An adult should always maintain responsibility for children with special needs.

SOME FINAL THOUGHTS...

Your school and your classroom will be part of the child's world. You need not feel pity for this child; in fact, to do so is a great disservice. With proper placement and arrangements, the student with albinism will not require a disproportionate amount of the teacher's time, and you will not need to neglect other students in order to meet this child's needs. Many children with special needs or gifts are in today's regular classrooms. A child with albinism should be able to enjoy and learn just like any other child.

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ADDRESSES OF RESOURCES

American Foundation for the Blind, 15 West 16th Street, New York, NY 10011, 1-800-AFB-LIND, (212) 620-2000

American Printing House for the Blind, 1837 Frankfort Avenue, Louisville, KY 40206, (502) 895-2405

Council of Citizens with Low Vision, 600 North Alabama St., Suite 2300, Riley Tower 2, Indianapolis, IN 46204-1415, 1-800-733-2258.

Council for Exceptional Children, Division for the Visually Handicapped, 1920 Association Drive, Reston, VA 22091.

NAPVI (National Association for Parents of the Visually Impaired, 2180 Linway Drive, Beloit, Wisconsin 53511, 800-562-6265

NOAH (National Organization for Albinism and Hypopigmentation), 1500 Locust Street, Suite 1816, Philadelphia, Pennsylvania 19102, 1-800-473-2310

National Society to Prevent Blindness, 500 East Remington Road, Schaumburg, IL 60173, (312) 843-2020.

International Organizations Dealing with Albinism:

Albino Fellowship, 15 Goukscroft Park, Ayr, KA74DS, Scotland
Albinism Fellowship, P. O. Box 717, Modbury, S. Australia.
NOAH Puerto Rico, Inc., Carmelo Almodvar, Pres., Arecibo Gardens #70, Arecibo Gardens, Puerto Rico 00612.
Tanzania Albinos Society, H. J. Mwaimu, Gen. Sec., P. O. 9644, Dar Es Salaam, Tanzania,Tanzania.

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This booklet was developed by Julia Robertson Ashley as a component of the author's Major Practicum in the Ed.D. Program in Early and Middle Childhood Education at Nova University, Ft. Lauderdale, Florida, U.S.A.

APPENDIX I

PRESCHOOL BOOKLET:

"THE VERY YOUNG CHILD WITH ALBINISM"

The Very Young Child with Albinism:

Suggestions for Working With Infants, Toddlers, and Preschoolers With Ocular Albinism or Oculocutaneous Albinism

by

Julia R. Ashley

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The author wishes to thank the National Organization for Albinism and Hypopigmentation (NOAH), the National Association for Parents of the Visually Impaired (NAPVI), and educators throughout the United States who have shared in the development of this booklet.

Julia Robertson Ashley is a teacher in the Anderson County (S. C.) School District 2. This booklet was developed as part of the author's major practicum in the Ed.D. Program in Early and Middle Childhood at Nova University, Fort Lauderdale, Florida. Information contained herein was derived from research conducted as part of the author's coursework in the master's degree program for exceptional children: visually handicapped at the University of South Carolina and in the doctoral program at Nova University. Mrs. Ashley, the 1991 Outstanding Student of the Year (Division for the Visually Handicapped/Council for Exceptional Children) has 18 years of experience in teaching and is certified in special education of the visually handicapped, media, English, and social studies. She is the mother of a child with albinism.

This booklet is designed for parents and teachers of infants, toddlers, and preschoolers with albinism. While this condition can be diagnosed at birth, often the condition is not diagnosed until age 1 or older. You may be wondering how to work with this child, what his/her future has in store, and what to *do*. You may be feeling nervous, anxious, and overwhelmed. Don't worry--this is normal.

A child with albinism is like any other small child, and needs love and acceptance. As long as you have those two qualities to share, the visual disability itself will not prove to be overwhelming.

This booklet is written as an introduction to the needs of children with albinism. It includes sources of support services as well as suggestions from parents and teachers who have been through what you are now experiencing. An excellent source that you should obtain is Parenting Preschoolers: Suggestions for Raising Young Blind

and Visually Impaired Children, by Kay Alicyn Ferrell. It is one of the best sources found by this writer, who used the suggestions not only as a teacher but also as a parent. Good luck, and don't ever be afraid to ask for help. We all had to ask for help at some point!

What should you expect from a child with albinism?

This little one has the characteristics of any other infant, toddler, or preschooler. He or she needs love, understanding, patience, and discipline. You may need to help adapt your environment in some ways, but these will not cause major disruptions in home or classroom life.

One of the most obvious problems that the child will have is an extreme sensitivity to sunlight or bright lighting. Outdoors, use sunglasses and caps with bills to reduce bright light. Indoors, make sure bright lights are shaded, use curtains to reduce bright glare, and seat the child out of bright light conditions.

A child with albinism has what is called "low vision." This means that the child has usable vision, but it is much less than a normally sighted

child. A child with albinism may see rather well from up close, but will have difficulty seeing objects from a distance.

What is albinism?

Albinism is any congenital hypopigmentation (lack of pigmentation), which can occur in plants, animals, and humans. In the human being, it affects the eye in the form of reduced visual acuity and nystagmus, and causes moderate to serious visual impairment. It has been speculated that Noah of Biblical fame had albinism (Sorsby, 1958). Most people have seen individuals with extremely fair skin and hair, and may have been told that a person was an "albino." Yet few people in the general public realize that all persons with albinism also have a serious visual disability. This condition is inherited through recessive genes. This means that both parents must carry the same rare gene for a particular type of albinism. It is possible for several children in a family to have albinism, but there is only a 25% chance that a pregnancy will result in a child having the condition (Haefemeyer, King, and LeRoy, 1986). The condition is found in approximately one out of every 17,000 people in the United States. Even with the limitations of low vision, individuals with albinism can live normal lives when they have appropriate support and resources. As adults,

they have families and jobs and participate in community activities.

Common characteristics of children with albinism include nystagmus, strabismus, photophobia, a lack of depth perception, and skin that is easily sunburned. Nystagmus is the involuntary and rapid horizontal movement of the eyes, which causes a reduction of visual acuity. Strabismus is the lack of coordination between the two eyes (they don't appear "straight"). There also is a lack of depth perception. The child will have great difficulty in judging distances and spatial concepts but can often compensate for these difficulties. Photo- phobia is an extreme sensitivity to light which can cause reduced acuity in vision.

The child with albinism at home/in class

Treat the child with albinism as you would any other. Don't feel awkward using terms such as "look" or "see"--these are normal parts of this child's vocabulary, too. Sometimes adults worry that they may say the "wrong" word or phrase around a child with a disability. A child who is classified as legally blind or visually disabled may have a great deal of useful vision for educational purposes (Bailey & Hall, 1990). Don't let the terminology make you uncomfortable. The child knows if he or she is loved and accepted, and

won't resent a person asking questions. It's OK to ask the child to look and describe what he sees. This may be the most practical way you may have of finding out what his visual field or functional level may be.

Years ago, children with visual problems who were not functionally blind were called "partially sighted." The current accepted educational terminology is "low vision." Low vision is insufficient vision to be able to do a desired task. Low vision children have a serious visual disability, but are able to use their vision for functional purposes, as opposed to children who are functionally blind (Barraga & Erin, 1991) and who use other senses as their primary mode for reading and academic learning.

What does "legally blind" mean?

Children with albinism have a wide range of acuities varying from 20/80 to 20/800. You should know the individual child's acuity and functional abilities for everyday life. A typical child with albinism might have an acuity listed as 20/200, which is considered legal blindness. Legal blindness is a term defined by the American Medical Association in 1934 and adopted by the U. S. Congress in 1935 in order to define eligibility for special services for the blind. Legal blindness is defined as "central visual acuity of

20/200 or less in the better eye with corrective glasses or central visual acuity of more than 20/200 if there is a visual field defect in which the peripheral field is contracted to such an extent that the widest diameter of the visual field subtends an angular distance no greater than 20 degrees in the better eye" (Scholl, 1986, p. 26).

In simpler terms, this means that if his or her vision is classified 20/200, the child can see from 20 feet what children with normal vision can see from 200 feet. Near vision (reading distance) may, or may not, be much better; the child might have nearly normal reading abilities when holding a book three or four inches away from the eyes.

Discipline

You should expect the child with albinism to follow rules just as any other child would. Encourage the child to move quietly about the room as necessary to obtain the best view of activities. The child may need some assistance to know where to stand so as not to block another child's view.

The child with albinism at times might not seem to respond to visual communications and clues from a distance such as the nod of a head indicating a child's turn to answer a question. This is probably because he cannot see them! It may be difficult for this child to recognize facial

expressions or hand gestures. Use verbal cues as well as physical ones.

The very young child with albinism

When working with infants and toddlers with albinism, movement activities and learning strategies used with normally sighted preschoolers are appropriate. Outdoor activities should be included, but it is important to make certain that sunshades or sunglasses are utilized with even the smallest children. OshKosh B'gosh makes a train conductors hat in very small sizes which could fit babies of only a few months of age. Another useful product is the sunglasses line by Baby Optics. They make sizes including newborn, baby, toddler, and kid. These have a high UV protection level, are priced under $15.00, and were recommended by a mother who had used them since her child was under one year of age. These products are found at many baby specialty stores. Any use of tinted lenses should be discussed with a parent who should make the decision in consultation with the child's eye specialist.

As the child becomes preschool age, it may be a good idea to gently talk about albinism with the child. Other adults may have mentioned the condition in the child's presence, thinking that the remarks wouldn't be understood. One mother of a 3-year-old reported her daughter telling her that

she had "pink eyes." The mother used crayons to draw pictures of a child with pink eyes and a child with darker colored eyes. The little girl decided herself that she did not have "pink eyes." But "little pitchers have big ears" and the children often may have a misunderstanding of the condition of albinism. According to Dr. Anne L. Corn, Professor at the University of Texas at Austin, one effective technique to use with a preschooler might be to allow the child to hold a magnifier and talk about Sherlock Hemlock, the detective character on Sesame Street. Dr. Corn recommends as young as age 4 introducing children to a monocular (a small, hand-held telescope). This is not to say that the child should be responsible for the monocular, but that parents should show it to the child and allow the child to use it on trips to practice looking more closely at distant objects. If a child is accustomed to using low vision devices at a very early age and realizes the advantages of using them, there is likely to be a reduction of resistance to using them in school, according to Dr. Corn. One parent reported using an inexpensive pair of Big Bird binoculars with a child with albinism who was only 2-years-old. The little girl enjoyed looking through the colorful, low-powered binoculars and began to understand the concept of using visual devices, even though the term "visual devices" was

never used. It was just a toy used like any other child which could also pave the way for future understanding.

Photophobia and glare

Children with albinism usually have photophobia, which is an extreme sensitivity to light. The teacher should seat the child away from windows and glaring light. If the child is seated near windows, there may be too much glare from reflected light. The child's vision may fluctuate from day to day, and can be affected by fatigue, emotions, and medication.

Glare is a distinct problem for children with albinism. Visors or eye shields may be useful in reducing overhead light and glare. The adult should take care not to stand with his or her back to the window in a room. The glare from the window makes it difficult for the child with albinism to look at others. It is normally difficult for a child with albinism to maintain eye contact; to attempt to do so with glare compounding the condition is virtually impossible. The child will need to be shielded from uncomfortable light.

Outdoor activities & special events

Your child with albinism will be able to participate in most activities with only minor modifications, but special consideration should be

given to certain matters of safety.

Assembly or group presentations. Most schools allow the youngest children to sit near the front with the older students in the rear of the lunchroom, auditorium, or similar area. The child with albinism may need to sit closer to the stage or to use a monocular in order to see adequately.

Field trips. Informing staff members at museums or theaters that you have a child with a visual disability. If they are informed in advance, special arrangements can be made to allow the child to get a closer look or even touch some exhibits. In unfamiliar surroundings, a child with low vision is at a greater disadvantage, so alert the adult to whom the child's group is assigned.

Physical education classes and outdoor activities. Outdoor activities may be difficult for the child with albinism. Activities that involve sports such as softball and basketball may cause difficulty for these children, due to the visual problem. Other sports, such as track, swimming, and aerobics, can be enjoyable for the child with albinism, and they can perform well in these areas. Young children enjoy playing in sand and in wading pools, and most other activities enjoyed by other preschoolers. The photophobia may cause discomfort for outdoor activities, but use of ball caps, eye shades, tinted lenses, and sunscreens can help the child enjoy outdoor

activities. However, Janice Knuth, president of the National Organization for Albinism and Hypopigmentation (N.O.A.H.), pointed out that there is a trade-off in using tinted lenses--tint reduces discomfort from glare, but it also reduces clarity and detail. Children with albinism may resist using sunglasses because they feel they do not see as well when wearing them.

Outdoor games played in the shade with well-defined boundaries for movement work well. Children may feel unsure of playground equipment such as slides because of the glare, but enjoy the equipment when they have partners. Yellow balls and colored bases make ball games more visible for the child with albinism. Small ball games (tennis, badminton, softball, baseball) are extremely difficult for children with albinism, due to both the size and speed of the balls; games involving larger balls work much better. Swimming, aerobics, gymnastics, track, horsemanship and skiing are sports that can be enjoyed with minimal adaptations required.

Fire drills. Do not ask another child to assist the child with albinism during drills or actual fires. The visually limited child may need assistance during an emergency, and children can panic or forget in these situations. It is unrealistic and unfair to expect another child to take the responsibility for a peer. An adult should always

maintain responsibility for children with special needs.

Some final thoughts...

Your home, preschool, daycare facility, church, or other institution will be part of the child's world. You need not feel pity for this child; in fact, to do so is a great disservice. With proper placement and arrangements, the child with albinism will not require a disproportionate amount of the adult's time, and you will not need to neglect other children in order to meet this child's needs. Many children with special needs or gifts are in today's regular preschools, centers, or classrooms. A child with albinism should be able to enjoy and learn just like any other child.

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Bailey, I. L. & Hall, A. (1990). Visual impairment. New York: American Foundation for the Blind.

Ferrell, K. A. (1984). Parenting preschoolers: suggestions for raising young blind and visually impaired children. New York: American Foundation for the Blind.

Haefemeyer, J. W., King, R. A., & LeRoy, B. (1986). Facts about albinism. Minneapolis: University of Minnesota International Albinism Center.

Scholl, G. (1986). Foundations of education for blind and visually handicapped children and youth. New York: American Foundation for the Blind.

Sorsby, A. (1958). Noah--an albino. British Medical Journal, 12, 1587-1589.

RESOURCES

American Foundation for the Blind, 15 West 16th Street, New York, NY 10011, 1-800-AFB-LIND, (212) 620-2000

American Printing House for the Blind, 1837 Frankfort Avenue, Louisville, KY 40206, (502) 895-2405

Council for Exceptional Children, Division for the Visually Handicapped, 1920 Association Drive, Reston, VA 22091.

National Association for Parents of the Visually Impaired (NAPVI), 2180 Linway Drive, Beloit, WI 53511, 1-800-562-6265

National Organization for Albinism and Hypopigmentation (NOAH), 1500 Locust Street, Suite 1816, Philadelphia, PA 19102, 1-800-473-2310

This booklet has been developed as a component of the author's major practicum in the Ed.D. Program in Early and Middle Childhood Education at Nova University, Ft. Lauderdale, Florida. 1992

APPENDIX J

BROCHURE ANNOUNCING PARENT WORKSHOP

Beacons

The [illegible] Chapter
of the National Association for
Parents of the Visually Impaired

Dear Parents:

Our president, [illegible], and her husband [illegible] have moved to Alaska, due to [illegible]'s tranfer with the Army. I will be scheduling events and handling paperwork for the Beacons group until new elections are scheduled.

We have a workshop planned for those of you who would like to have some help with planning your children's IEPs. Mrs. Julia Ashley, member of our group and a doctoral student in education at Nova University, will be presenting a program for parents of low vision students. There will be a second session immediately following specifically for parents of children with albinism.

The workshop will be held on Saturday, May 23, at 210 South Murray Avenue, [illegible], from 11:00 am until 12:30. Because many of you may not be able to attend, Mrs. Ashley has volunteered to be available for telephone conferences Monday through Friday evenings from May 11 until May 29, during the hours of 7:00 pm till 9:00 pm. You can also reach her on weekends if needed, but she will be working with some parents and teachers during these times. Just leave a message on her answering machine if she is not home, & she can get back with you. Her phone number is 338-9593 (a [illegible] number).

We hope that this will be a beneficial service to you, and hope to get the newsletter out this summer. With [illegible] moving, it has affected a lot of our usual operations. Thanks for your patience!

APPENDIX K

REQUEST FOR PARTICIPATION OF National Organization for Albinism & Hypopigmentation MEMBERSHIP

1032 Trail Road
Belton, SC 29627
November 22, 1991

Ms. Janice Knuth
National Organization for Albinism & Hypopigmentation
1500 Locust Street
Suite 1816
Philadelphia, PA 19102

Dear Ms. Knuth

I would like permission to have National Organization for Albinism & Hypopigmentation members evaluate the preliminary draft of a booklet for teachers of children with albinism. I am a graduate student at Nova University working on the educational needs of school aged children with the condition of albinism.

I am attempting to devise a booklet for teachers of students with albinism. I would like to send copies of the proposed educational strategies to National Organization for Albinism & Hypopigmentation members in order to assess their view of the appropriateness of the strategies.

I will make available to National Organization for Albinism & Hypopigmentation copies of any material produced in this effort at no cost to National Organization for Albinism & Hypopigmentation. I will not give access to this mailing list to any others.

I hope to hear from you and your board soon.

Sincerely,

Julia Ashley

1. Title of Proposed Project:

Developing Practical Application Strategies for Teachers of Students with the Visual Disability of Albinism

2. Primary Investigator

Julia Robertson Ashley
1032 Trail Road
Belton, South Carolina 29627
home--(803) 338-9593
work--(803) 369-2933; 369-7612
B.A., M.A.T., Ed.S.
Certified Teacher in South Carolina & New Jersey for 18 years
Mother of child with albinism (Mary Lin Ashley; age 3 years)

3. University Affiliation:

Nova University, Ft. Lauderdale, Florida
Ed.D. Program in Early & Middle Childhood
Abraham Fischler Center for the Advancement of Education

4.

(A) Objectives:

To inform special education teachers, regular classroom teachers, and support personnel of educational strategies which will benefit children with albinism. This project will be geared toward the visual aspects of albinism due to the requirements of the writer's doctoral program.

(B) Questions to be addressed

What techniques are most effective with children with albinism? What special needs might a child with albinism have which would be different from most visually impaired students?

(C) Methods:

a. Evaluation of results of a 1990 regional survey of teachers of the visually handicapped and national survey of parents of students with albinism, conducted by the writer as a student in the masters program in education of visually handicapped students at the University of South Carolina.

b. Survey of international contacts regarding the educational needs of students in their countries.

b. Review of pertinent educational literature concerning albinism

c. Review of related medical literature

d. Development of booklet for use by teachers of students with albinism.

e. Dissemination of booklet to teachers & parents in the United States, Canada, and Europe.

f. Survey via checklist inside booklet to determine opinion of parents and teachers as to validity and usefulness of booklet.

5. Numbers, ages, and types of subjects to be contacted:

Teachers of the visually handicapped, Parents of children with albinism, Adults with albinism. Numbers of persons unknown at this time; the object is to contact as many as possible to get as wide a range of responses as possible. Contact will be made with individuals in the United States, Canada, and Europe.

6. Method of contacting participants:

Through the U. S. mail, via a survey checklist.

Copies of the booklet are to be disseminated to parents of children with albinism and teachers who have participated in the practicum. The attempt will be made to have the booklet available to parents and professionals at the National Organization for Albinism & Hypopigmentation national convention in Chicago, Illinois, in July, 1992.

Self-addressed, stamped envelope (or possibly a post card) will be included with each booklet for participant's convenience in assessing the validity and usefulness of the booklet.

7. Proposed plan for publication:

This project is being done as a component of the Major Practicum in the Ed.D. Program in Early and Middle Childhood of Nova University. Plans for publication include consideration for submission to the ERIC database of educational research maintained by the U. S. Department of Education.

8. I will send to National Organization for Albinism & Hypopigmentation a copy of all publications resulting from this research at no cost to National Organization for Albinism & Hypopigmentation. I understand that National Organization for Albinism & Hypopigmentation will not participate in any financial manner. I assume all costs for this work.

Dear National Organization for Albinism & Hypopigmentation Member,

I am a graduate student in the Ed.D. Program in Early and Middle Childhood Education at Nova University. This contact is an attempt to determine appropriate educational interventions which have been effective with students with the etiology of ocular albinism or oculocutaneous albinism.

The nature of this project is to request analysis by parents and educators of children with albinism in regard to educational techniques. Participation involves filling in the enclosed questionnaire after reading strategies (see enclosure). The results of this study will provide teachers of children with albinism with more information on the condition and on educational procedures which will help the children be as successful in school as possible. The information will also benefit parents and support workers in understanding how albinism affects a child's school work.

Your participation is completely voluntary. Information on this questionnaire will be anonymous and held in strict confidence. Only group results will be reported. If you have any questions, please call Julia Ashley at (803) 338-9593.

Information on the results of this study will be published in the NOAH News and I hope to have a booklet for teachers prepared by August, 1992. I appreciate your participation in this work.

Sincerely,

Julia Ashley

Evaluation Form
Under Consideration

Please read the enclosed When You Have a Child With Albinism in Your Classroom: Tips for Teachers and Support Staff. Consider the information provided, and answer the survey questions listed below. Please send this to Julia Ashley in the enclosed envelope. Please include any suggestions and comments you feel appropriate.

SCALE:
5 = Strongly Agree
4 = Agree
3 = Uncertain
2 = Disagree
1 = Strongly Disagree
NA= Not Applicable

1. The information provided is appropriate for students with albinism.

5 4 3 2 1

2. Teachers already have an understanding of the condition of albinism and would not need this information.

5 4 3 2 1

3. This information would help my child's teacher(s) to better serve my child's educational needs.

5 4 3 2 1

4. I wish that I had been able to obtain this information when I learned of my child's visual disability.

5 4 3 2 1

5. This information will be helpful to medical and social work personnel to assist in explaining the needs of children with albinism.

5 4 3 2 1

APPENDIX L

LETTER OF RESPONSE FROM PRESIDENT OF N.O.A.H.

(NATIONAL ORGANIZATION FOR ALBINISM AND HYPOPIGMENTATION)

NOAH
National Organization for
Albinism and Hypopigmentation
1500 Locust Street, Suite 1816
Philadelphia, PA 19102

April 22, 1992

Mrs. Julia Ashley
1032 Trail Road
Belton, SC 29627

Dear Mrs. Ashley:

Thank you very much for writing the booklet The Student With Albinism in the Regular Classroom and allowing NOAH to publish it. The booklet contains a great deal of information that is helpful to our members.

Since my letter to NOAH members and friends on March 27, 1992, in which I gave information about your booklet, we have received many orders for it from parents, schools, and libraries. Some orders have been for multiple copies. As one parent said, there is nothing else like it available.

I am also finding the booklet helpful in my work as Coordinator of Social Services at Wills Eye Hospital in Philadelphia when I see families with children who have albinism.

NOAH will continue to inform members and friends about the booklet through our newsletters. We expect to receive many more orders for it. We will also make it available at our National Conference in Chicago in July.

The booklet is a very great contribution to improved education for children with albinism. I congratulate you on your accomplishment.

Very sincerely yours,

Janice L. Knuth

Janice L. Knuth, MSW, ACSW, LSW
President

BEST COPY AVAILABLE

215 545•2322 1 800 473•2310

APPENDIX M

LETTER OF RESPONSE FROM PRESIDENT OF N.A.P.V.I.

(NATIONAL ASSOCIATION FOR PARENTS OF THE VISUALLY IMPAIRED)

• support
• information
• service

800-562-6265

Officers

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At-Large

Grant Nicolai
Alexandria, VA

NAPVI is a non-profit organization.

NAPVI's officers and board members serve on a volunteer basis.

NAPVI
2180 Linway Drive
Beloit, WI 53511-2720

April 22, 1992

Julia Ashley
1032 Trail Rd.
Belton, SC 29627

Dear Julia,

NAPVI would like to tell you how pleased we are to have been involved with your publication, "The Student With Albinism in the Regular Classroom". Since NAPVI has made the official announcement in its" publication the AWARENESS we have received many orders. We have had many more calls from parents who have children with Albinism and they are all anxious to get a copy of your publication.

We with to thank you for giving NAPVI the opportunity to be a part of this fine publication and we wish you much success in the future.

Sincerely,

Eileen Hudson

Eileen Hudson,
NAPVI President

APPENDIX N

REQUEST FOR PARTICIPATION OF
MEMBERSHIP OF ALBINO FELLOWSHIP

1. Title of Proposed Project:

   Developing Practical Application Strategies for Teachers of Students with the Visual Disability of Albinism

2. Primary Investigator

Julia Robertson Ashley
1032 Trail Road
Belton, South Carolina 29627, U.S.A.
home--(803) 338-9593
work--(803) 369-2933; 369-7612
B.A., M.A.T., Ed.S.
Certified Teacher in South Carolina for 18 years
Mother of child with albinism (Mary Lin Ashley; age 3 years)

3. University Affiliation:
   Nova University, Ft. Lauderdale, Florida
   Ed.D. Program in Early & Middle Childhood
   Abraham Fischler Center for the Advancement of Education

4.

(A) Objectives:

To inform special education teachers and regular classroom teachers of educational strategies which will benefit children with albinism.

(B) Questions to be addressed

What techniques are most effective with children with albinism? What special needs might a child with albinism have which would be different from most visually impaired students?

(C) Methods:

a. Survey of teachers of the visually handicapped

b. Review of all educational literature concerning albinism

c. Review of related medical literature

d. Development of booklet for use by teachers of students with albinism. Consideration is being given to attempting to provide the booklet in both English and Spanish.

e. Dissemination of booklet to teachers & parents.

f. Survey via checklist inside booklet to determine opinion of parents and teachers as to validity and usefulness of booklet.

5. Numbers, ages, and types of subjects to be contacted:

Teachers of the visually handicapped, Parents of children with albinism, Adults with albinism. Numbers of persons unknown at this time; the object is to contact as many as possible to get as wide a range of responses as possible. Contact will be made with individuals in the United States, Canada, and Europe.

6. Method of contacting participants:

Through the U. S. mail, via a survey checklist.

Copies of the booklet are to be disseminated to parents of children with albinism and teachers who have participated in the practicum, and to be provided to parents and professionals at the National Organization for Albinism & Hypopigmentation national convention in Chicago, Illinois, United States of America, in July, 1992.

Self-addressed envelope will be included with each booklet for participant's convenience in assessing the validity and usefulness of the booklet.

7. Proposed plan for publication:

This project is being done as a component of the major practicum in the Ed.D. Program in Early and Middle Childhood of Nova University. Plans for publication include consideration for submission to the ERIC database of educational research maintained by the U. S. Department of Education.

8. I will send to the Albino Fellowship a copy of all publications resulting from this research at no cost to the Albino Fellowship. I understand that the Albino Fellowship will not participate in any financial manner. I assume all costs for this work.

(LETTER TO MEMBERS OF
ALBINO FELLOWSHIP)

1032 Trail Road
Belton, SC 29627
U.S.A.

<first> <last>
<add>
<city>, <province>
<country> <zip>

Dear <first> <last>,

I am a graduate student in the Ed.D. Program in Early and Middle Childhood Education at Nova University in the United States of America. I am also the mother of a three year old child with albinism and a school teacher with eighteen years of experience. I am, as part of my graduate studies in the education of children with visual impairments and blindness, attempting to create a booklet for teachers of children with albinism.

I was given your name by the Albino Fellowship, an organization which is interested in helping us be able to better serve our students' needs. Please fill out the information on the enclosed survey and return it to me at the address listed above.

The results of this study will provide teachers of children with albinism with more information on the condition and on educational procedures which will help the children be as successful in school as possible. The information will also benefit parents and support workers in understanding how albinism affects a child's school work.

Your participation is completely voluntary. Information on this questionnaire will be anonymous and held in strict confidence. Only group results will be reported.

Information on the results of this study will be submitted to the Albino Fellowship for their newsletter.

Sincerely,

Survey About Albinism

Please return to:
Julia R. Ashley, 1032 Trail Road, Belton, South Carolina 29627 USA.
Thank you for participating in this effort to improve educational practices for children with albinism.

1. Which best describes your involvement with albinism?

__Parent of Albino __Educator __Medical __Albino __Other Professional

2. Are educational services to visually impaired children in your local schools provided by:

____ Regular teacher ____ Special Teacher of the Visually Impaired

____ Regional Consultant ____ Other (explain)

3. Are children with albinism generally accepted by other children or rejected by them?

4. Are visual aids (glasses, magnifiers, spectacles, etc.) provided by the government, local agencies, or privately funded by the family of the child?

5. Do you believe that teachers understand the visual needs of students with albinism?

6. Are individuals with albinism in your country usually able to operate an automobile? ___ yes ___ no

What is the usual means of transportation for them?

7. Are materials for students with albinism provided in:

____ large print ____ Braille ____ Auditory Tape

_____ regular print (may be more than one)

There is a plan to publish a booklet to be used by teachers of children with albinism. If you would like to receive a copy (free of charge) when published, please fill in your name and address below:

Name:

Address:

City, Province:

Country

APPENDIX O

NOAH INFORMATION BULLETIN

"ASSISTING STUDENTS

NOAH

Information about
Albinism

National Organization for Albinism and Hypopigmentation

Assisting Students with Albinism

Most students with albinism can participate in general education programs with proper intervention. Since not all children with albinism have the same visual acuity, and since not all use their vision with the same efficiency, it is important to consider each child with albinism as an individual.

According to a federal law, the Individuals with Disabilities Education Act (IDEA or PL 101-476), school systems must provide education in the "least restrictive environment" to children with disabilities. The program must meet the child's individual needs. For most children with albinism, this environment is the "mainstream" classroom, in which a vision resource teacher finds ways to allow the student to participate in usual activities.

A vision resource teacher is a special education teacher with expertise in visual impairment. To identify a vision resource teacher and to access special education services, parents of a child with albinism should contact their public school system's administrative office. This contact should occur well before kindergarten. In some localities, services are available to children before the age of three, and the school system can provide information about these. Beginning at age three, as required by Public Law 99-457, public school must provide services to children with disabilities. For children with low vision, these services will include assessment of visual function and suggestions to parents about ways to help their child. This assessment paves the way for the school system to develop an Individual Education Plan (IEP) at age 5. The child may participate in a preschool for children with disabilities or a regular preschool at the parents' discretion.

The Classroom Setting

The student, his or her parents, classroom teacher, vision resource teacher, and optometrist or ophthalmologist must work as a team. The team should consider seating, lighting, materials, and social and emotional growth, as well as the use of appropriate optical aids.

The student, classroom teacher, and vision teacher should discuss classroom seating. Most students will sit in the front row, but not all can see the blackboard even from there. Some students will not wish to sit up front and should not be forced to do so, but should be provided with the information in other ways. The seating position should avoid glare from the side windows and overhead lights, and should avoid shadow. In a classroom with fluorescent lights, a seat between banks of lights is better than one directly under a bank.

The student may need to move to a different seat to see movies or filmstrips. Many students with albinism will have trouble reading from overhead projector screens because of glare. The student may copy the acetate sheets from the overhead projector as the teacher finishes using them. Or the student may ask to copy another student's notes. Or another student may take notes on carbonized paper and give the original to the student with low vision.

Use of Large Type

Students with albinism may or may not need large print. The team should look at the distance and near vision acuities from the eye examination. The vision teacher should observe the student

working with various print sizes. Each spring the vision teacher can gather all books the class will use during the following year and review the books with the student to ascertain which need to be enlarged. Contrast is probably more important than print size in making this determination. The student's judgment as to which books need to be enlarged is important.

Standard classroom materials through the third grade use primary size type, which is sufficiently large for those with low vision. By the third or fourth grade, it may be advisable to enlarge math books because some of the symbols are quite small. Students may be willing to use large print in school in the fourth through sixth grades. But by junior high they may not want to use large print in the classroom because of peer pressure. They may be willing, however, to use the large print books at home.

Books for typing class usually need to be enlarged and placed on a slanted reading stand because it is not possible to get close to the print while typing. Likewise, music scores for band and orchestra instruments usually need to be enlarged due to the distance from which they must be viewed.

For those students who require large print books and materials, the vision teacher usually can obtain large-type versions of the usual classroom textbooks either from the American Printing House for the Blind in Louisville, Kentucky, or from other companies that reproduce texts in large type. In some cases, the local education agency must photo-enlarge the textbook themselves. Junior and senior high school students may prefer tape recordings rather than large type.

Teacher-prepared handouts may be photo-enlarged or read to the student. By photocopying, it is often possible to increase the contrast of low contrast text materials and drawings.

Standardized achievement tests may need to be photocopied and enlarged, since the test booklets usually are to be reused and cannot be marked in, and the print is small. The machine scored answer sheets which accompany the booklets are in very small print. The task of looking from test booklet to answer sheet and back, over and over, is extremely difficult for visually impaired children. When the test is enlarged, the student can mark answers directly on the booklet. Later, the answers can be transferred to a machine scored answer sheet. PSAT's and SAT's are available in large print and on cassette under untimed conditions.

Nonoptical Aids to Vision

Computers can be of great use to students with low vision. Students with albinism should begin to learn keyboarding skills with typing readiness computer games as early as kindergarten; they should begin direct instruction in typing or keyboarding as early as the third grade. Computers with large screen monitors and software for large character display may help older students with writing projects.

CCTV (closed circuit television) may help students to read charts, graphs, pictures and text. When using CCTV, try inverse polarity (white letters on black background) to reduce glare.

Optical Aids

For reading, the student with albinism may use stand magnifiers, hand-held magnifiers, or special reading glasses, such as bifocals with a strong reading lens or telescopic reading lenses clipped over glasses.

Contact lenses may help for distance vision. Some students use monoculars (small hand-held telescopes). Older students may use bioptic lens systems, which can improve reading and distance vision. Bioptics incorporate telescopic lenses into standard glasses, to allow the student to use either the standard correctional lens or a telescope for intermediate or distant vision. Some bioptics may include two different telescopes— one for distance and one for reading— mounted in the same carrier lens. Newer designs of bioptics use small lenses that are lightweight and cosmetically more acceptable, but may be more difficult to use because of a smaller field of vision. (More information is available in NOAH's "Low Vision Aids" information bulletin).

In consultation with the vision teacher, an optometrist or ophthalmologist experienced in low vision should prescribe specific aids for the individual student. In the doctor's office the student should have the opportunity to try all types of aids and to select the most comfortable type of aid for a given visual task.

After an aid is prescribed, the vision teacher works with the student while he or she learns to use it properly. Low vision clinics should allow students to use aids on a trial basis, and to return them if the aids are not helpful. To review the usefulness of an aid, the student should return to the doctor about one month after an aid has been prescribed.

The American Foundation for the Blind maintains a directory of low vision clinics throughout the United States. (Address: AFB, 15 West 16th Street, New York, NY 10011. Phone: 800-AFB-LIND, hours 8:30 a.m. to 4:30 p.m. Eastern time.)

Students often are reluctant to use optical aids because the aids draw attention. To be like everyone else, students may avoid using the aids and pretend to be able to see when they cannot. Younger students may hide, lose, or break their glasses.

Physical Education

The school staff needs to find ways to include students with low vision in all activities, and to avoid leaving them sitting on the sidelines. "Small ball" games (tennis, badminton, softball, baseball) are difficult for children with albinism, due to both the size and speed of the balls. Games involving large balls work much better (kickball, basketball). Yellow balls and colored bases make ball games more visible for the child with albinism. Swimming, aerobics, gymnastics, track, horsemanship and skiing are sports which can be enjoyed with minimal adaptations required.

Social Support

Teachers must avoid drawing attention to the student with albinism. Students with oculocutaneous (skin as well as ocular) albinism stand out in any case, and may require emotional support for responding to their classmates. Parents can help their children deal with teasing or other forms of discrimination by encouraging them to share their experiences and their feelings about them. Conferences including the student, teacher, vision teacher, and parent may help to support a student. Some families in NOAH have found it helpful to give a presentation to the class about albinism, along with a general discussion about respect for differences.

Alternatives to Mainstreaming

Though most children with albinism will be able to succeed in a mainstreamed setting, sometimes the least restrictive environment for a child may be a half-day resource room with other visually impaired, or a special class, or even a special school for the visually impaired. The child may require education outside the mainstream classroom because the child's self-esteem is very low, or the child's skill levels are below those of his classmates, or the child emotionally cannot deal with the demands of the regular grade placement.

If such problems require removing a child from the mainstream classroom, it is important that the educational team plans for working on these problems in specific ways, such as group or individual counseling as part of the school day, individually designed remedial instruction in weak areas, or individual instruction in study skills, organization skill and social skills. It is important to place a time limit on such placements, and review goals and progress closely.

In considering alternatives, note that children with albinism do not benefit from braille, and if given trials of braille, they read it visually.

No single approach works for all students with albinism. However, with patience, understanding, and hard work, the team can find ways for a student to function successfully in the general education program.

For Parents: An IEP for Your Child

The Individual Education Plan or IEP is an important part of the education process for the visually impaired student. The IEP is the blueprint for the coming year. It describes adaptations and modifications required by students to compete with their sighted counterparts. For parents and students, this meeting sometimes proves intimidating and filled with uncertainty, but it helps for parents to understand the process and their rights.

Parents should prepare for the meeting by understanding its purpose, and their rights under the Individuals with Disabilities Education Act. In addition to the federal law, many states have enacted state regulations and the local school district may have its own guidelines. Parents can obtain copies of these laws and regulations from the school system.

Parents need to bring a list of questions to the meeting. They need to take the attitude that they have at their disposal the collective knowledge of the professionals who will be at the meeting.

It is important to have the most current report from the child's ophthalmologist or optometrist. This report is helpful, along with input from the vision teacher, in determining the best modifications to the classroom environment and print materials.

Parents should keep a file with past IEP reports and most recent reports by the school psychologist, social worker, and other educational evaluations necessary for meeting federal, state and local IEP regulations. Parents may request these reports from the appropriate school personnel.

There will be at least three people present at the IEP team meeting: the vision teacher, a school administrator, and a parent. It is important that both parents attend the IEP meeting—it does make a difference. Others attending the meeting might include the school psychologist, social worker, and other special education professionals such as a speech teacher. The child may also attend the IEP meeting.

Parents should keep in mind that they know their child best. They should listen to their child, and advocate for him or her. It is helpful to hear out the presentation, take notes to remember the points that seem uncertain, and ask questions after the report. Parents should not sign the IEP until they have read it and agree with its contents. However, they may be asked to sign a form that states they were present at the meeting, though the IEP is not yet written.

Common ideas about low vision may not apply to the child in question. In particular, large print or pre-recorded text materials are not always appropriate, and should not be accepted as substitutes for poor visual aids. The IEP allows parents of children with visual disabilities to advocate a program tailored for their child.

Consultants for this bulletin include Sidney C. Wharton, a vision resource teacher in Fairfax County, Virginia, public schools; Nan Dempsey, retired supervisor of programs for the visually impaired for the State of New Jersey; and Julia Ashley, a doctoral student at Nova University who is studying the needs of students with albinism. Further information will be available in Ms. Ashley's booklet, The Student with Albinism in the Regular Classroom, published by NOAH and NAVPVI in 1992. The Innovating Worthy Projects Foundation of Somers Point, NJ, funded publication of this bulletin.

For more information, contact:

National Organization for Albinism and Hypopigmentation
1500 Locust Street, Suite 1816, Philadelphia, PA 19102
Phone 1-800-473-2310

APPENDIX P

LETTER OF RESPONSE FROM CHILDREN'S SERVICES DIVISION,
SOUTH CAROLINA COMMISSION FOR THE BLIND

south carolina commission for the blind

1430 CONFEDERATE AVENUE • COLUMBIA, SOUTH CAROLINA 29201
TELEPHONE 734-7520

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Florence

HARRIS W. HOLLIS
Member
Columbia

Mrs. Julia R. Ashley
1032 Trail Road
Belton, South Carolina 29627

Dear Julia:

How impressive! Your booklet "The Student With Albinism in the Regular Classroom" is beautifully written and a wonderful resource. Thank you so much for giving us permission to copy it for parents and counselors and teachers in South Carolina. Needless to say, we copied it immediately. Thank you also for the acknowledgement to Judy and me. As we've said many times, we receive much more from our parents and children than we give.

Please give my best regards to Allen and Mary Lin. I am sure they are so very proud of their published professional mom! Thanks again for sharing your expertise.

Sincerely,

Elizabeth M. McKown
Supervisor, Children's Services

EMM/

APPENDIX Q

LETTER OF RESPONSE FROM DR. MARVIN EFRON, PH.D.

EYE ASSOCIATES OF CAYCE-WEST COLUMBIA
600 KNOX ABBOTT DR., P.O. BOX 4045
CAYCE-WEST COLUMBIA, S.C. 29171
PHONE (803) 794-4444
DRS. EFRON, ANTLEY, DAVIS, ADAMS, RIVERS, BAILEY & KLECKLEY
OPTOMETRISTS

Feb 15, 1992

Dear Julia,

Just finished reading your publication "The Student with Albinism in the Regular Classroom". You did an outstanding job & it is an asset to the field. Thanks for my copy.

Keep up the good work.

Sincerely,
Mami

APPENDIX R

ANNOUNCEMENT OF PUBLICATION OF BOOKLET IN
JOURNAL OF VISUAL IMPAIRMENT & BLINDNESS , JUNE, 1992

poverty level. In 1991, the poverty level for a household comprised of one person aged 65 or over was $6,532, and the near-poverty level $8,165; for a two-person household headed by a person aged 65 or over, the poverty level was $8,238 and the near-poverty level $10,297. For more information, contact the Administration on Aging, U.S. Department of Health and Human Services, 300 Independence Avenue, S.W., North Building, Room 4760, Washington, DC 20210, 202-245-0724.

Education

Teaching children to play

Independent Living: A Curriculum with Adaptations for Students with Visual Impairments is a three-volume set that covers social competence, self-care, maintenance of personal environment, play and leisure. The set is available for $35 from the Texas School for the Blind and Visually Impaired, 1100 West 45th Street, Austin, TX 78756-3494; 512-454-8631; fax 512-454-3395.

Introduction to albinism in school

The Student With Albinism in the Regular Classroom by Julia Robertson Ashley, is an introductory booklet addressed to regular teachers in elementary and secondary schools and for school administrators, counselors, nurses, and other school personnel. The practical guide is available for $3.50 from the National Association for Parents of the Visually Impaired, 2180 Linway Drive, Beloit, WI 53511; 800-562-6265 or the National Organization for Albinism and Hypopigmentation, 1500 Locust Street, Suite 1816, Philadelphia, PA 19102, 800-473-2310.

Curriculum for social-skills training

Partially Sighted Children & Social Skills: A Training Programme is designed for psychologists, teachers, or other professionals working with visually impaired children. It covers nonverbal cues, personal presentation, conversational skills, peer situations, adult situations, anger control, listening skills, telephone skills, and loneliness. The complete package, which includes large-print response sheets, role-play cards, an audiocassette for voice exercises, and follow-up materials, is available for $40 from Child and Adolescent Services, Royal Blind Society, 4 Mitchell Street, Enfield, NSW 2136, Australia; 02-334-3333.

Culture-sensitivity for service providers

Developing Cross-Cultural Competence: A Guide for Working with Young Children and Their Families, edited by Eleanor W. Lynch and Marci J. Hanson, includes contributions by representatives from the following ethics groups: Anglo-European, Native American, African-American, Latino, Asian, Filipino, Native Hawaiian and Pacific Island, and Middle Eastern. The book, which covers such topics as culture-specific beliefs about disability, health, and childrearing, can be ordered for $32 from Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285; 800-638-3775 or 301-337-9580.

Curricula for different ages and abilities

The following publications are available from Services for Independent Living, 25100 Euclid Avenue, Suite 105, Cleveland, OH 44117-2663; 216-731-1529; fax 216-731-3083:

- *Discover the World of Independent Living* ($15) is designed for teaching students aged 13 to 19 with developmental disabilities; it also includes suggestions for adaptations for students with visual, auditory, or orthopedic impairments. The complete package includes a teacher's guide and supplemental syllabus.
- *Just Like You and Me* ($15) is a disability-awareness curriculum for fourth- and fifth-grade students, and it includes adaptations for use with a variety of grade levels. The package includes a teacher's guide with instructions for participatory activities, a movie, posters, a skit, simulations devices, and braille alphabet cards.
- *Moccasins of Disability* ($15) is a disability awareness curriculum for college-level students in education, nursing, rehabilitation counseling, or other areas related to health or social science. It can be adapted for use in a quarter-, semester-, or summer-length workshop.
- *Focus on Ability* ($15) is a disability awareness curriculum for students in grades 6 to 12. It covers the history of public attitudes about disability, their relationships, choices, and personal experiences. It also includes a guide to classroom activities, worksheets, a bibliography and a resources appendix.
- *With Feeling* ($15) is a college-level curriculum for training professionals who work with parents of newly diagnosed children with disabilities to be sensitive to disability issues.

Audio report

Cassette explains ADA to parents

As part of the American Foundation for the Blind's (AFB) Initiatives to Implement the ADA and to provide information to parents of children who are visually impaired, AFB has released a two-track, 90-minute cassette that presents an overview in simple, conversational language of Title I (employment) and Title III (public accommodations) of the ADA, as they relate to issues important to parents of blind or visually impaired children. The package includes a complete recording of a teleconference with the government relations staff of AFB and members of the legislative committee of the National Association for Parents of the Visually Impaired and a related discussion guide. To order, send $12.95 plus $3 shipping to AFB, 15 West 16th Street, New York, NY 10011; 212-620-2155; fax 212-620-2105.

Bible on cassette in 33 languages

The Bible Alliance is offering a recorded version of the Bible, available in 33 languages free of charge to anyone who provides verification of a visual or reading impairment. To receive a verification form or for more information, contact the Bible Alliance, Inc., P.O. Box 621, Bradenton, FL 34206; 813-748-3031; fax 813-748-2625.

Health and eye care

Ophthalmological index

The American Academy of Ophthalmology is offering the ten-year cumulative index of *Focal Points: Clinical Modules for Ophthalmologists*, the clinical update series that covers clinical topics for eye-care physicians. The index is available with an annual subscription to *Focal Points*, at $85 for Academy members and $110 for nonmembers. For more information, contact the American Academy of Ophthalmology, P.O. Box 7424, San Francisco, CA 94120-7424; 415-561-8540.

Working with children with CVI

Cortical Visual Impairment in Children: A Handbook is a booklet for parents and professionals working with children with CVI. Written by an occupational therapist, it includes a neurological definition of CVI, descriptions of associated diagnoses, causes, and prognoses; information

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